ABSTRACT

PHYSICAL AND PSYCHOLOGICAL DEVELOPMENT
OF CHILDREN WITH CONGENITAL HEART DISEASE

By

Thomas Taflan-Barrett

The present study examines the effect of congenital heart disease on a child's physical and psychological development. Fourteen children with histories of chronic congestive heart failure, thirteen with chronic cyanosis, seventeen with serious heart disease without chronic symptoms, and fourteen with insignificant heart disease formed the four main sample groupings.

The assessment of each child consisted of an interview with one or both parents, followed by the recording of height, weight, and head circumference measurements and the administration of a battery of psychological tests. Children younger than 30 months were assessed using the Bayley Scales of Infant Development--Mental Scale and Motor Scale, and the Denver Developmental Screening Test. Children older than 30 months were assessed using the Stanford-Binet Intelligence Scale and the Denver Developmental Screening Test (if younger than six years of age).

During the parent interview, family background information and information regarding the pregnancy and the newborn period was collected. Each mother was also asked to complete a modification of the Neonatal Perception Inventory which assesses maternal attitudes regarding the first six months of her child's life.

It was found that severity of illness did not correlate strongly with physical development (except with weight gain) or with psychological development (except with psychomotor functioning). It was expected that children with histories of chronic congestive heart failure or cyanosis would be more physically retarded, on all three measures, and psychologically delayed, on all psychological indicies.

However, the study did find that, when physical retardation was observed, regardless of the severity of illness, psychological delays could also be anticipated.

The study also found no differences between children operated on using profound hypothermic techniques and those undergoing other procedures.

The limitations of this study, especially those involving sample availability and data collection techniques, are discussed. In addition, suggestions for more extensive, further research in this area are offered.

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PHYSICAL AND PSYCHOLOGICAL DEVELOPMENT

OF CHILDREN WITH CONGENITAL HEART DISEASE

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DEDICATION

To the Memory of

Michael Brandon

and to my parents,

Ralph and Elizabeth Barrett

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CHAPTER ONE

THE PROBLEM

Introduction

Today, a child born with a heart defect, has a better chance than ever to overcome the handicap and progress toward a normal adult life. Surgical techniques that were impossible as recently as twenty years ago are now employed routinely in medical centers and children's hospitals throughout the world.

It is estimated that there are as many as 35 different kinds of congenital heart defects, some 20 of which can be repaired or at least partially corrected by surgery. Even so, congenital heart anomalies remain a major cause of death in infancy.

Of all the infants born annually in this country, approximately one percent have a congenital defect, either within the heart itself or in one or more of the major blood vessels by which it is served. In some instances a child may suffer from a combination of defects and often survives only because one defect is compensating for another.

Heart defects are often found in infants born with other anomalies. Rubella babies and babies born with Down's syndrome and Marfan's syndrome frequently suffer from various forms of heart defect.

The German measles virus has long been known to be a cause of cardiac abnormalities especially when the mother is infected during the first two months of pregnancy. Other viruses probably also cause heart defects, even when the infection is so mild the mother is not actually aware of any illness. Other teratogenic agents such as radiation,

drugs or injury may also be causative but only during the first two gestational months when the embryo's heart is being formed.

There is some evidence to suggest a family basis for heart defects. Some family histories reveal a predisposition for cardiac ailments. When a couple has a child with a heart defect they are usually advised that they have about a two percent chance of having a heart ailment in any other children they may produce. This is about double the risk for the rest of the population. Parents with heart defects themselves have a slightly higher chance--about three percent--of giving birth to progeny that will also be affected.

Not only is it difficult to determine the cause of a heart ailment, it is also usually hard to understand why a particular type or combination of defects develops. As has been seen, teratogenic agents can affect the heart during the first two gestational months but the form of the resulting defect varies considerably. Some affected embryos never come to term. Others are able to survive on their mother's life systems but die at or shortly after birth.

Etiologically then, heart disease still holds many mysteries, and although great progress has been made in the development of techniques to correct the defects, a great deal remains to be learned as well about how these defects affect the individual. Are there critical periods in an infant's development when he is greatly affected by the presence of the ailment? In the past it was advisable to wait as long as possible before surgically intervening in a heart case. Larger hearts in bigger, stronger bodies promised greater chances of successful repair than did the heart of a tiny infant. The advent of

profound hypothermia techniques[1] in the last few years, has made intervention possible at younger and younger ages. However, it is still uncertain what the long term effects of profound hypothermia are in terms of brain functioning and/or the performance of other bodily organs.

It has long been observed that children with heart disease tend to express growth retardation to a much greater degree than unaffected children. It is only recently that the reasons for the occurrance of this growth failure are beginning to be understood. However, our knowledge at this point remains far from conclusive.

Need

While a number of studies in the past have examined the problem of pyhsical growth failure in children with cardiac disease, virtually no attention has been paid to cognitive and motor development in these children.

A study which would concern itself with these three parameters simultaneously, as well as the interrelationships between them, could go far to contribute to our knowledge of cardiac disease. It might also provide helpful information to cardiologists and psychologists alike in their work with these children.

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[1]Profound hypothermia during surgery involves lowering the patient's body temperature 15-20 degrees until organ functioning essentially ceases. When this technique is employed in conjunction with a by-pass machine that does the work of the patient's heart and lungs the surgeon is able to work on a motionless heart in an essentially bloodless field for as long as 60-70 minutes without serious physical danger to the patient.

Purpose

The purpose of this study was to assess the physical, cognitive and psychomotor development of infants and children with congenital heart defects in an attempt to determine whether children expressing physical growth retardation also show concomitant retardation in cognitive and psychomotor development. In addition, pertinent medical and psycho-social data concerning these children and their families were collected and examined for trends and similarities.

With this in mind, the study directed itself toward two goals:

1. To collect physical, social and psychological development information regarding a number of children with heart defects. Survey this data for any similarities or trends and if possible identify any patterns that may become evident.

2. To formally assess the physical, cognitive and motor development of each child and compare and contrast this information in lieu of their respective defects and symptomatologies.

Hypotheses

Broadly stated, the hypotheses are as follows:

1. Children with cardiac defects tend to exhibit physical growth retardation more frequently than do less-afflicted children.
2. Children with cardiac defects tend to exhibit lags in cognitive development more frequently than do less-afflicted children.
3. Children with cardiac defects tend to exhibit lags in motor development more frequently than do less-afflicted children.

4. Children with cardiac defects who express growth failure will similarly tend to lag in cognitive and motor function development.
5. Profound hypothermia techniques employed at the time of surgery do not adversely affect the child.

Theory

Numerous studies support the hypothesis that undernutrition in infancy may detrimentally effect brain growth and eventual intellectual functioning. This is well documented with both animal and human subjects.

Correa (1908), DeSilva (1964), and Stoch and Smythe (1968) found that malnourished infants tend to be deficient in the areas of exploratory behavior, curiosity and general activity level when compared with typical healthy infants.

Brockman and Ricciuti (1971) found deficiencies in sensory discrimination in malnourished infants.

Cravioto and Robles (1965), Monckenberg (1968), Stoch and Smythe (1968), and Chase and Martin (1970) all noted gross differences in psychomotor performance between healthy and malnourished infants based on performance as measured by standard infant scales.

Birch and Gustow (1970) found apathy to be a characteristic behavioral feature of the clinical syndrome of malnutrition.

Winick (1970) found in both animals and humans, that when malnutrition occurs during the period of cell division (i.e., before the age of six months) the resultant brain has fewer cells than the normal brain.

Lester (1975) found attentional defecits in malnourished infants which the author considered likely to interfere with learning.

If this be the case for non-cardiac children affected by severe malnutrition, we are left to wonder whether similar results hold for children with growth failure secondary to cardiac defect. As will be noted in the literature review chapter, some authors feel that strong similarities exist between the physiologic states of severe malnutrition and growth failure associated with cardiac disease.

There exists much variability among children with heart defects. The severity of the physical condition, whether or not the child's symptoms (i.e., cyanosis, congestive heart failure, etc.) are of an acute or chronic nature, the effects of surgical intervention, the age at time of such intervention and the techniques employed, all must be considered in each case.

One might also wonder whether or not certain types of defects or certain symptomatologies are more or less associated with detrimental development. Are there other variables (i.e., prenatal, physical, social-emotional, environmental, etc.) which correlate with such development? Each of these issues are addressed in this study.

Overview

Chapter two considers the functioning of the normal heart and examines the effects of various cardiac defects. Chapter three is devoted to a review of the literature concerning growth failure and cardiac anomalies. In chapter four the design of the study is described including an examination of the sample population and an explanation of the measures to be used. Chapters five and six provide analysis of the results and a discussion and summary of the findings.

CHAPTER TWO

THE NORMAL HEART AND CONGENITAL HEART DEFECTS

The normal heart is a hollow organ composed chiefly of muscle. Even in adulthood it weighs well under a pound and is about the size of an individual's clenched fist. The heart wall itself is composed of muscle called the myocardium. This is lined on the inside by a thin, strong membrane called the endocardium; and is covered on the outside by an outer sac called the pericardium.

Inside the heart there are four chambers. The septum divides the heart vertically into left and right halves. Each half is further divided forming an upper chamber, the atrium, and a lower chamber, the ventricle. In each half of the heart the atrium serves as a filling or storage chamber and the ventricle as a pumping chamber. These upper and lower chambers are separated by valves which are formed from flaps which open in only one direction, allowing blood to drain downward from the atrium to the ventricle.

After circulating through the body, blood returns to the heart, low in oxygen and dark red in color. This blood enters the right atrium and flows through the tricuspid valve into the right ventricle where it is pumped through the pulmonary arteries to the lungs (see Figure 1). In the lungs the carbon dioxide in the blood is exchanged for fresh oxygen which returns the bright red color to the blood. It is then returned to the heart through the pulmonary vein. This oxygenated blood then re-enters the heart through the left atrium and flows

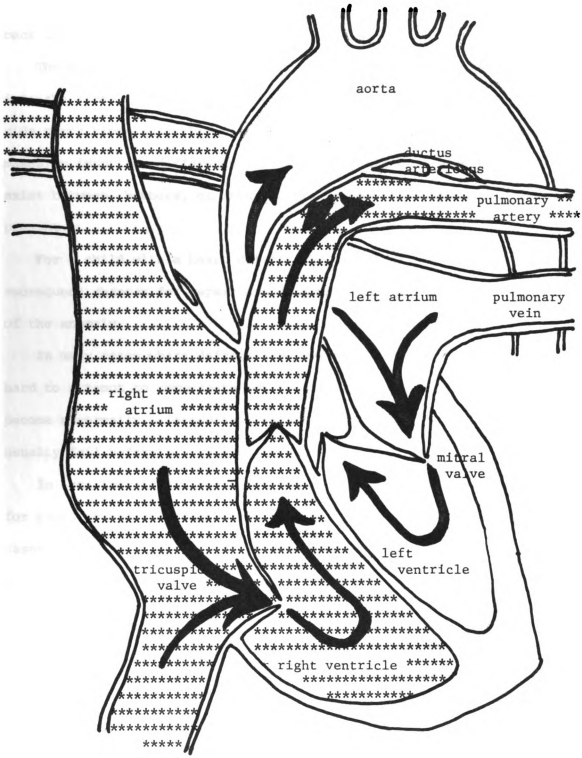

Figure 1: The normal heart: Arrows indicate blood flow, shaded areas represent unoxygenated blood, clear areas represent oxygen-laden blood.

through the mitral valve into the left ventricle where it is pumped back into the body through the aorta.[2]

The pressure with which the left side of the heart forces blood into the aorta is much greater than the pressure with which the right side pumps blood into the pulmonary artery. This gradient in pressure makes an important difference in circulatory blood flow when defects exist between chambers, or when valvular or arterial anomalies are present.

For a child with a heart defect, the extent of his handicap and his subsequent chances for repair are determined by the nature and severity of the anomaly.

In many cases where defects are present the heart may work extra hard to attempt to compensate for the error in development and may become abnormally enlarged as a result. Such an enlarged heart will usually fail before too long.

In some individuals heart defects are so small they go undetected for years or even for an entire lifetime. In others, especially some cases involving patent ductus arteriosus, the defect may correct itself in time.

For most cardiac cases however, surgery, if possible, remains as the only option. It is estimated that about 90 percent of children born with cardiac defects can be cured or at least helped by surgery.

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[2]Information for this chapter was obtained from the following sources:

Apgar, J., & Beck, J. Is My Baby Alright? New York: Trident Press, 1972.

Phibbs, B. The Human Heart: A Guide to Heart Disease. (3rd ed.) St. Louis: C. V. Mosby Co., 1975.

Indications of cardiac malfunctioning may be evident at birth. A low Apgar score[3] may be diagnostic, especially if cyanosis is present or if an abnormal heart beat or respiratory problems are evident.

Once a defect is suspected, time becomes an important ally. The first month of life is often the most critical (the first few days for some defects) as the baby completes his transition from relying on the placental respiratory system to using his own.

In severe cases where cyanosis is present and respiratory distress persists, it is usually necessary to perform a cardiac catheterization as soon as possible. A cardiac catheterization can serve two functions. Primarily it is a diagnostic tool. Dye is injected into a predetermined chamber and its progress through the heart and lungs is monitored by consecutive x-rays which are taken and then viewed sequentially. The catheter tube can also be used diagnostically to collect blood samples or measure pressures in the various chambers.

Catheterization has another function especially in some cases involving newborns. As was mentioned earlier some children survive only because they have one defect compensating for another (i.e., transposition of great arteries). For the child without a complimentary defect, modifications such as creating a hole between the artria, can be performed, enabling the child to survive until complete surgical repair can be attempted.

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[3]The Apgar score, developed by Dr. Virginia Apgar, is a system used to evaluate an infant's physical condition at one and five minutes after birth. Heart rate, respiration, muscle tone, color and response to stimuli are scored 0, 1, or 2. The maximum score for a normal baby is 10. Infants with low scores usually require immediate attention.

Some risk is involved in cardiac catheterization, especially for very young or very sick babies. Such a procedure is often necessary however, to determine the exact nature of a defect and the subsequent repair required.

When surgical intervention is deemed necessary it will either involve the major vessels outside the heart, the heart itself, or both. In the past the term "closed heart surgery" was used to refer to a limited kind of surgery within the heart. In such surgeries the heart was kept beating or stopped for only a few minutes while the surgeon made a small opening and used either a gloved finger or a small instrument to effect a repair in an area he could not actually see.

Surgical techniques have improved greatly, primarily as the result of the advent of the "heart-lung machine." This device, sometimes referred to as a bypass machine, intercepts the blood before it reaches the heart, oxygenates it, and returns it to the body via the aorta. As a result, "open-heart surgery" is possible and enables the surgeon to completely open the heart allowing him to suture patches, ream out stenotic vessels and in some cases even rebuild damaged chambers and passageways. The heart-lung machine can function in place of the patient's heart and lungs periodically for hours if necessary.

Heart defects can be generally divided into two major categories: hypoxic or cyanosis inducing defects which result from right-to-left shunting of the blood and non-hypoxic defects or those which involve left-to-right shunts or communications between the chambers that do not result in cyanosis. We will first consider some of those which involve the latter type or left-to-right shunts.

Patent Ductus Arteriosus (PDA)

At birth every child has a ductus arteriosus which is an open passageway between the two major blood vessels, the pulmonary artery and the aorta. In the post-natal infant or child, the pulmonary artery carries blood from the right ventricle to the lungs where it is re-oxygenated. The aorta sends this oxygen-laden blood from the left ventricle out to the body.

In the normal infant the ductus closes within a few weeks of birth and is usually closed within the first 10 to 15 hours. If this fails to happen, as it does in about one in 2,000 (Apgar, 1972), some of the blood that should go through the aorta to nourish the rest of the body returns to the pulmonary artery and is sent back to the lungs. It is in this way that a PDA causes a left-to-right communication between these two vessels, blood leaving the left side of the heart is returned to the right side without ever going out to nourish the body. As a result, the heart works harder to pump sufficient blood to the body. If the opening or ductus is very large the child's growth may be slowed, probably due to lowered systemic (aortic) blood flow.

Patent ductus arteriosus is one of the most common of all cardiac defects and was the first to be able to be corrected surgically. It is now considered one of the easiest surgical repairs and carries one of the lowest operative risk factors. To correct this abnormal circulation pattern the surgeon does not have to open the heart. Instead, he merely closes the ductus permanently by a tying off and cutting procedure. In most cases, where there are no other malformations, this is enough to effect a cure in the patient.

Septal Defects: Atrial Septal Defect (ASD), Ventricular Septal Defect (VSD)

Another common cardiac defect is caused by a hole in the septum or wall of tissue which divides the heart into left and right sides. This defect may be found in any portion of the wall between the two lower chambers, the ventricles (ventricular septal defect), or between the two upper chambers, the atria (atrial septal defect). Occasionally, both upper and lower chambers may be involved.

The opening may be very small, cause no serious problems and never need treatment. Or, it may be very large, problematic and even fatal to the child if repair is not effected. In some rare cases a whole section of the septum may be missing.

Any opening in the septum makes it possible for oxygenated blood to flow from the left side of the heart where pressure is greater back to the right side of the heart, mixing with the unoxygenated blood.

An artrial septal defect can be detected by a characteristic heart murmer. It usually does not produce serious symptoms in a young child, although in some cases it can result in growth retardation. There are serious complications which can develop in later life however, and for this reason, doctors advise that unless the hole is very small it should be corrected surgically at a convenient time during childhood.

The repair procedure requires open-heart surgery employing the heart-lung machine. The hole in the septum is sewn shut during the procedure or, if it is very large, a teflon or dacron patch may be sutured over the site. This is a permanent patch which gradually becomes covered over by living tissue as the child grows. Following the procedure, if the pressures in the various chambers remain constant

and stable and if no other malformations are detected, repair is considered to be complete.

A ventricular septal defect, between the lower chambers, is considered more serious. It too can be identified by a characteristic heart murmer. Because the ventricles are the pumping chambers of the heart, much more pressure is exerted on the blood passing through the communication making it difficult even for a small hole to close on its own. This does occur occasionally, however, by a process that is still not completely understood. In fact about twenty percent of all VSD's correct themselves in this fashion.

Some children with small defects may be essentially asymptomatic. In others, the opening may be so large that it may cause congestive heart failure, growth retardation, pulmonary complications and death.

Since higher pressure is exerted by the left ventricle during heart muscle contraction the oxygenated blood gets shunted, via the VSD, into the lung vessels at an increased pressure. This may eventually cause thickening in the walls of the lungs. In addition, since the heart is forced to work harder to get enough blood to the body, the ventricle may eventually become enlarged.

As in atrial septal defects, children with ventricular septal defects also tend to express growth failure. They are also inclined to develop pulmonary hypertension and congestive heart failure.

In some cases a palliative procedure is required before complete repair is attempted. In this procedure a band is put around the pulmonary artery to make it smaller. The effect is that more resistance is offered to pulmonary blood flow and the effect of the septal defect is thus minimized.

When a complete repair is performed the procedure is similar to that for an ASD. The hole is either sutured closed or a patch is inserted.

We have so far considered the three major left-to-right shunting, or acyanotic defects (PDA, VSD, ASD). Now, we will consider four defects that result in cyanosis, or blue-coloring, in a child, due to unoxygenated blood recirculating through the body or a minimal amount of blood reaching the lungs to receive oxygen. These are: Transposition of the great arteries, pulmonary atresia, tricuspid atresia and tetralogy of Fallot.

Transposition of the Great Arteries (TGA)

This is one of the most serious of cardiac anomalies as well as one of the most difficult to treat. It is the most lethal of all during the first two months of life, resulting in 18 to 20 percent of all infant deaths from congenital heart disease. It affects many more males than females.

In this malformation, as its name suggests, the pulmonary artery and the aorta are transposed so that the right ventricle pumps carbon dioxide laden blood into the aorta returning it to the body while the left ventricle pumps oxygenated blood into the pulmonary artery, returning it to the lungs.

As may be expected, a child born with this defect cannot survive at all unless he has some other defect that allows left-to-right shunting or mixing of the blood. In other words, the child must also have a patent ductus, an atrial septal defect, or a ventricular septal defect, or a combination of two or more of these additional anomalies to allow

some oxygen-rich blood to escape from the left heart and lungs to the right heart and transposed aorta.

Such a complementary defect however, does not fully correct the problem. The length of time such a child can survive is dependent upon how effectively the blood is mixing.

A child with a transposition is usually identified in the first few days of life. He is almost always cyanotic. Respiratory problems are also often observed. If a child with a transposition does not have a septal defect to allow blood mixing, one is created for him by the cardiologist at catheterization. This usually involves forming, or enlarging a hole between the two atria.

Occasionally in cases of transposition, growth failure is observed in the child. Because of recent advancements in hypothermic techniques, complete surgical repair can now be attempted at a very early age and is often performed during the first year of life.

Pulmonary Atresia (PA)

The pulmonary valve is one of the most common valves of the heart to be affected by narrowing or stenosis. When this occurs the flow of blood from the right ventricle to the lungs may be greatly inhibited. As a result, the supply of oxygen to the rest of the body is reduced. The heart pumps harder in an attempt to make up for the deficit, resulting in an enlarged right ventricle, right atrium or both.

This right side enlargement along with increased right ventricular pressure assists the cardiologist in diagnosing the defect. Cyanosis is usually evident as well and the activity of a child with pulmonary atresia may be greatly reduced and his growth rate may be delayed.

Other defects often co-exist with PA, most notably a hole in the septum between the two ventricles.

The optimal time for surgery for a child with pulmonary atresia depends upon the severity of the child's clinical course prior to surgery and varies from individual to individual. During the repair the pulmonary valve may be opened with special instruments. Or, if the valve is severely damaged, it may be replaced with a synthetic valve.

Tricuspid Atresia (TA)

In this defect, the tricuspid valve between the right atrium and ventricle has no opening or is absent. As a result, blood cannot pass between the chambers. For the child to survive other defects must also be present, usually in the form of an atrial septal defect and a ventricular septal defect.

The normal pattern of blood circulation is considerably altered. Since it has no passageway to the right ventricle, blood returning to the right atrium from the body flows through the atrial septal defect into the left atrium. Here it mixes with fresh blood returning from the lungs and drains through the mitral valve into the left ventricle. Next a portion of the mixed carbon dioxide and oxygenated blood is pumped out to the body. The rest of it, flows through the ventricular septal defect into the right ventricle. From here it is finally pumped through the pulmonary artery to the lungs. Some blood therefore, makes extra, unnecessary trips to the lungs while some recirculates through the body without receiving fresh oxygen. As a result, children afflicted with tricuspid atresia are cyanotic. They, too, may be delayed in development.

Tetralogy of Fallot (TOF)

Tetralogy of Fallot gets its name from Dr. Etienne Fallot, a French physician who, in 1888, wrote a book about four kinds of heart defects which sometimes occur together in the same patient. Since that time this particular group of defects has been known medically as tetralogy (group of four) of Fallot.

A child with such a defect has the following four anomalies: (a) a ventricular septal defect allowing communication between both ventricles, (b) the aortic root is dextro-posed, or moved rightward, allowing blood from each ventricle to flow out of the body; part of the blood with fresh oxygen and part without, (c) pulmonary stenosis, or narrowing of the pulmonary valve and sub-valve area, which limits the amount of blood going to the lungs, (d) enlargement of the right ventricle caused by exerted pumping required to force blood through the narrowed pulmonary valve.

Children with tetralogy of Fallot are not only cyanotic but may express growth retardation and "clubbing" at the ends of their fingers and toes. An older child with a tetralogy may experience shortness of breath after exercising and may squat or have fainting spells because of insufficient oxygen reaching the body and brain.

Since total repair in infancy is difficult and dangerous, palliative procedures may be employed to allow the child to grow before more extensive surgery is attempted. There are two procedures which may be used. In one the surgeon creates an artificial shunt by fastening a smaller artery, which branches off from the aorta, to the pulmonary artery. This allows more blood to reach the lungs.

In another procedure the aorta and pulmonary artery can be joined at one small juncture, once again allowing for more pulmonary blood flow.

Complete repair of these four defects is a complicated and rather long procedure. The septal defect must be closed or patched. The flow must be properly directed. The pulmonary valve and artery must be repaired and stenotic tissue in the ventricles may need to be painstakingly removed.

It may have been noted in the seven defects reviewed above that growth retardation or developmental dealy is often seen in children with heart defects. In many cases however, normal development is observed. Several studies conducted in the past 25 years have attempted to understand the cause of such growth retardation as well as what causes it to occur so irregularly both within a given defect and across all defects. These studies are reviewed in the following chapter in an attempt to determine what factors, if any, may be causitive.

CHAPTER THREE

A REVIEW OF THE LITERATURE

Growth Failure and its Relation to Congenital Heart Disease

What is growth failure? Clinically it is defined as the patient being at or below the third percentile (two standard deviations from the norm) for height, weight, and head circumference.

In an article published in 1959, Mazur estimated that congenital heart disease was the second most common cause of growth failure.

Most of the early studies, those published in the late 40's, the 50's, and early 60's considered growth failure in relation to the type of cardiac defect, differentiating between patent ductus arteriosus (an extracardiac lesion) and other defects which occur within the heart. Porter (1947), Adams and Forsyth (1951), Engle, Holswade, Goldberg and Glenn (1958), and Umansky and Hauck (1962) all considered patients with PDA's with sample sizes ranging from 3 to 444. Their findings were similar. Children with patent ductus arteriosus tended to be smaller than the norm. Correction of the lesion only sometimes contributed to an improved growth pattern and for the most part results were likely to be better if surgical repair was completed at an early age.

As to why growth failure occurred, the authors felt the results to be inconclusive. It may have been caused by a number of factors in addition to the cardiac defects. In some cases there were other congenital anomalies and it was felt that prematurity, low birth weight and environmental influences may also have been contributory.

Engle, et al. (1958) were concerned with the apparent persistance of growth retardation after successful surgery. They were primarily concerned with determining whether or not there is an optimal age for surgical intervention. Or phrased another way, is there a "critical period" for growth and development?

In all they reviewed 52 cases of PDA from records at the New York Hospital and from the literature. From one-third to one-half of the patients were undergrown physically with low weight being the most evident problem. Age at time of surgery ranged from 3 to 14 years. The results showed that the more undergrown a child before surgery, the less he would improve afterwards. They concluded by recommending early surgical intervention whenever growth retardation began to become evident.

In an eight year period from 1959 to 1967 a number of articles appeared dealing with intracardiac lesions and the subsequent occurrance of growth failure. Robinson and Bayer (1969) provide a review of some of these articles, including, Mazur (1959), Mehrizi and Drash (1962), Schlange (1962), Barbaccia, Macchi, and Corsini (1964) and Linde, Dunn, Shiresen and Raffos (1967).

In summarizing the studies, Robinson and Bayer report that growth retardaion, in general, seemed to vary according to the type of lesion and its functional effects. Retardation was especially associated with cases involving either chronic congestive heart failure or chronic cyanosis. Weight retardation tended to be more common than height retardation. Boys tended to be more physically retarded than girls but cyanotic girls tended to be more delayed as they got older.

Some delay in secondary sexual development was also noted in children with defects of all types and skeletal retardation was associated with retardation in both weight and height but was not parallel to it.

The studies also suggest some possible factors that may be the cause of growth failure in cardiac children. The presence of either cyanotic symptoms or chronic congestive failure seemed contributory. Some non-cardiac but associated factors such as repeated infections, and genetic or familial linkages may have played a part and the degree of physical incapacity in the patient may also have contributed.

In children who have not had surgery they have found that by the second year of life these children tend to be smaller than the norm and their skeletal maturation is retarded. As they approach adolescence, however, their dimensions and skeletal development move closer to the normal means. At all ages they report that the ratio of sitting height to stature is larger than chronological age standards, indicating that the children are short primarily because they are short-legged.

In studying children who have already had surgery Robinson and Bayer found that growth patterns, especially weight patterns, tended to improve slightly but that no obvious "catch-up" phenomenon could be demonstrated.

The Robinson and Bayer study has many limitations. The authors do not differentiate their subjects on any criteria. They are only interested in comparing differences between pre- and post-surgical measurements. No information is given as to the types of cardiac ailments encountered, the severity of each case and the individual

ages at the time of surgery. Also, did all of the subjects survive surgery? If not, were the more severely undergrown ones the ones who died?

Several studies in the literature report a correlation between chronic congestive heart failure and growth retardation.

Adams, Lund and Disenhouse (1954) studied the growth data on 229 children with a variety of cardiac defects. They concluded that children with congenital heart disease do not necessarily express abnormal growth either in terms of physique or in rate of growth. They did observe however, that the presence of pulmonary congestion (congestive heart failure) did seem to be related to growth failure. They also suggest that growth failure in some children could be the result of non-cardiac factors including emotional disturbances.

In a 1963 study, Krovets studied weight gain in children with PDA. He reviewed 342 surgically corrected patients. Pre-operatively, 90 of these had been below the third percentile for weight. Post-surgically, the data on 72 of these patients revealed that 24 remained below the third percentile as late as two or more years after surgery. The author concluded that congestive heart failure pre-operatively and the presence of additional non-cardiac anomalies were more common in these children.

Ritter, Wallace and Weidman (1965), considered immediate and later results of the complete repair of severe tetralogy of Fallot. Approximately one-third of the 35 patients studied exhibited pre-surgical growth retardation. Post-surgically only one child remained below three percent and this child continued to be affected by chronic congestive heart failure as long as 18 months after surgery.

Lees, Bristow, Griswold and Olmstead (1965), studied relative hypermetabolism in infants with congenital heart disease and undernutrition. Twenty-one patients with congestive heart failure, arterial unsaturation (cyanosis) or both were compared to 21 normal controls with respect to resting oxygen consumption. The cardiac patients required significantly more oxygen with those expressing chronic heart failure symptoms requiring the most of all.

In a 1969 study, Feldt, Strickler and Weidman also leave these questions unanswered but they do provide some further important information. The authors studied 463 patients with a variety of cardiac defects, observing them both before and after surgery to assess their growth patterns. At the outset they noted no significant differences in birth weights between these patients and a group of normal children. Pre-operatively however, lower than normal mean weights were noted in the groups of patients with coarctation of the aorta, ventricular septal defect, tetralogy of Fallot, atrioventricular canal and patent ductus arteriosus. Patients with transposition of the great vessels had the lowest pre-operative weights averaging 2.4 SD below the normal mean. (The other groups ranged from 0.7 to 1.4 SD below the mean).

Pre-operative height was also measured. Groups of patients with ventricular septal defect, tetralogy, atrial septal defect and atrioventricular canal all averaged 0.5 SD below the mean. Transposition patients, though, averaged 1.5 SD below the mean.

Within each group the authors also identified those individual patients expressing growth failure (2 SD below the mean). They found 32% of transpositions, 19% of PDA's, 14% of VSD's and 10% of ASD's and atrioventricular canal patients fit the criteria. In addition, 8% of

the tetralogy and coarctation patients and 4% of the aortic stenosis and pulmonary stenosis patients also could be termed growth failure.

Post-operatively, improvements, though oftentimes very slight, were noted in every group. The greatest gains were noted in patients with ventricular septal defects, especially with cardiac failure in infancy, those with coarctation of the aorta and those with patent ductus arteriosus. The authors do not report age at the time of surgery but state that for both height and weight gains, it did not seem to be an influencing factor.

Perhaps the most interesting finding in the study had to do with the incidence of congestive heart failure. The authors report that growth failure occurred in children in all cardiac diagnoses studied and generally correlated with the severity of the lesion. However, the highest percentage of growth failure (33%) was found in children with VSD who had a history of congestive heart failure in infancy. Congestive heart failure in infancy was also common in children with PDA and TGA and these patient groups also exhibited high incidences of growth retardation.

They conclude from their data that congestive heart failure in infancy ultimately effects the growth pattern of a child. They suggest that it may have the same effect on subsequent development as does primary malnutrition.

Krieger (1970) was interested in the significance of insufficient intake in the growth failure of cardiac patients. He attempted to evaluate this by measuring the response to forced feeding in patients who, prior to it, had had adequate caloric intake on the basis of normal requirements for age and weight but who did not grow.

The anabolic response was excellent. On a comparable calorie intake, nitrogen retention and weight gain were similar to those of patients with growth failure in the absence of organic disease. Calorie requirements per unit of body weight were increased because the basal metabolic rate (BMR) was increased. This increase was not due to the heart disease because control patients with similar degrees of growth failure in the absnece of organic disease had a similar BMR.

In Krieger's opinion indications as to the cause of growth failure in cardiac patients becomes somewhat clearer. The child with a heart defect is given to frequent infections, pulmonary congestion and episodes of minor illnesses that may be accompanied by anorexia. During these periods, nitrogen retention decreases subsequently raising BMR per unit of body weight. The result is that the child requires a greater intake than would normally be expected.

A question arises: Why doesn't the child want to eat more? Krieger states that the cause of poor voluntary intake is not known. He says that it is unlikely that the physical condition is the cause, since the patient tolerates the forced feedings without need for additional digitalis (medication to prevent heart failure). He also states that food intake may be insufficient because of psychological factors that may be related to the presence of a chronic or life-threatening disease. These factors perhaps pay a heavy toll on the relationship between the cardiac baby and his family, resulting in poor attachment formation and what could be termed a psychologically "at risk" situation.

Naeye (1965a) has also been an important contributor to the research on the occurrance of growth retardation in cardiac cases.

He reports on a quantitative study of the organ and cellular development in 12 infants with congenital heart defects and seven suffering from alimentary malnutrition. His findings showed that most of the organ abnormalities observed in the two groups were similar, suggesting malnutrition as a common etiology. More specifically, he found that structural abnormalities in the pituitary, pancreas, and other organs suggested an anatomic basis for a variety of functional disturbances which the patients displayed. He noted that reatrded brain development appeared to be a serious consequence of such malnutrition. Unlike many other researchers, Naeye found a correlation between growth failure cardiac cases and subnormal weight and height at birth which he felt suggested retarded prenatal growth as well.

Naeye (1965b) followed immediately with a more extensive report of what he termed "dysmature" cardiac neonates. By carefully studying and measuring the bodies and organs of those infants who had died he determined that the problem was one of a subnormal number of cells in the babies. He therefore concluded on the basis of this study of 136 babies with obvious severe cardiac anomalies, that an embryo with a cardiac defect may show retarded growth in utero and that this may partially explain the slow postnatal growth and mental retardation occasionally associated with congenital cardiac anomalies.

In 1966 Naeye published the results of a study of 26 newborn infants with complete transposition of the great arteries. He found that their bodies and organs were enlarged due to increased cytoplasmic mass in the individual parenchymal cells. The same abnormality, along with the pancreatic islet hyperplasia and fetal zone adrenal enlargement, was found in infants with diabetic mothers. He suggests

as a result of this that the link between the two groups of infants may be hyperglycemia in the fetal pancreatic perfusate. In the diabetic cases the hyperglycemia seemed to be a reflection of maternal hyperglycemia and in the cardiac cases it seemed to be the result of an abnormal prenatal circulatory pattern.

A subnormal number of parenchymal cells was also found in most organs of newborns with TGA. Naeye states that this is also common in neonates with other cardiac malformations and may provide a partial explanation for the slow postnatal growth in many such infants.

The results of Naeye's most extensive study appeared in 1967. In this study he examined tissue abnormalities during postmortem examinations of 220 individuals with congenital cardiac malformations. The ages of the subjects ranged from birth to 44 years. They were compared with 91 controls ranging in age from birth to 37 years. In each patient, body weight, body length, and weights of organs were calculated in percent of mean values for control patients. Naeye specifically looked closely at the liver and adrenal cortex because previous studies had shown that reduction of cytoplasmic mass in their parenchymal cells is a sensitive index of undernutrition.

He found that infants with cardiac malformations were 92.4% as heavy at birth as would be expected given their gestational ages. This was only a marginal difference from the norm. As the infants grew older though, organ and body measurements became progressively more subnormal. For example, when hepatic cytoplasmic values were computed for cardiac infants they were within the normal range during the first few weeks of life, but for infants between 2 and 16 months their cytoplasmic value was only 59% of the control mean (significant at $p = .001$ level).

Naeye also payed special attention to brain size because of previous suggestions that undernutrition in congenital heart disease may lead to retardation in that organ during the early months. He reports that in stillborn infants brain weights as a group did not vary significantly from control values (97.5%, $p = .3$). At subsequent ages though, the relative postmortem weight of the brain progressively increased in infants with malformed hearts. As a group, infants aged 8 to 24 months had brain weights 87.1% of control values ($p = .01$). In this age range the weight of individual brains showed a direct relationship to the cytoplasmic mass in the hepatic cells. In contrast, most children over 3 years of age with cardiac defects had brain weights near control levels.

It is interesting to note that infants without cardiac defects dying of marasmus due to alimentary malnutrition also had a subnormal cytoplasmic mass in hepatic and adrenal cortex cells. As was noted in the previous chapter, numerous studies from nutritional literature show that in human beings and in animals alike, severe alimentary undernutrition during the first months of life may lead to permanent mental and motor dysfunctioning. It is only logical to be concerned as to whether or not the same is true of infants expressing growth failure due to cardiac defects.

Although cardiac patients seem to "catch-up" to non-cardiac patients by 3 years of age, at least on the indicies Naeye measured, do they "catch-up" in other categories? Especially, one must wonder about cognitive functioning and psychomotor development. Furthermore, one must wonder about the statistics used to evidence this reported

"catch-up" phenomenon. By 3 years of age some of the most severely affected patients must have died. With them removed from the subject pool the results are bound to improve.

Head Circumference Measurements as an Important Tool in the Assessment of Growth Failure

In virtually all of the studies referred to thus far, failure in physical development has, for the most part been determined by measurements of height and weight. Certainly these are very important criteria to be considered. However, since our purpose in this research is also to consider the psychological development of the child with congenital heart anomalies, we must also be concerned with the value of using head circumference measurements in our assessment of the child's development.

O'Connell, Feldt, and Stickler (1965), studied a group of 134 children with a head circumference more than 2 SD below the mean for their ages. All but one were mentally subnormal as measured by the Stanford-Binet test, the Infant Cattell Scale , and the Vineland Social Maturity Scale. The most severe mental retardation was noted in the group of children with a head circumference of minus 4 standard deviations or below. The authors also found, as others have, that mentally retarded children have heights and weights below the expected norms but that the children they examined with head circumferences below -2 SD had even lower mean heights and weights.

The authors also measured the head circumferences of 31 children who were termed "growth failure" because of height and weight measurements but who had normal intelligence scores. They found these

children's head sizes to be within normal limits. They concluded that in the child with growth failure, should the head be proportionately small (below -2 SD), mental subnormality should be suspected.

In lieu of this a 1973 study by Clarkson should be viewed as one of the most important regarding growth failure and cardiac defects. The study takes on added significance because it is the only study in the literature dealing with children with cardiac defects, all of whom underwent surgical repair at less than 1 year of age. Average age at time of surgery was 5½ months. Each child suffered from a large left-to-right shunt and each operation was performed because of life threatening hemodynamic disturbance in the patient.

All of the subjects in the study were more than 2 SD below the mean weight for age. All but one were more than 1 SD below the mean height for age ($6 \leq -2$ SD). On head circumference measurements, 2 were at or below -4 SD from the norm; 7 others were at or below -2 SD from the norm and only one child was not more than -1 SD. (He was below normal, however.)

The results of the study showed that weight which was below normal at the time of the operation came to lie within the normal range in most patients post-operatively. Linear growth showed little change. Head circumferences which were abnormally small at the time of the operation came to lie within the normal range in those patients whom these measurements were known to have been normal at an earlier age. It should be noted though, that more than half of the children remained in the range between -1 and -2 SD below the mean and only one child ever reached the norm.

Summary

Although the literature concerning growth failure and its relation to congenital heart disease is inconclusive, some trends become evident:

1. Growth failure occurs in virtually every category of heart disease.

2. In general, the more severe the case, the more likely it is that growth failure will become evident.

3. Chronic congestive heart failure seems to be strongly correlated with physical growth retardation.

4. In general, the earlier surgical intervention occurs, the better are the chances that growth retardation can be ameliorated.

CHAPTER FOUR

DESIGN OF THE STUDY

Sample

The population of this study consisted of fifty-eight children, ages five months through eleven years (mean age = 43 months), who were patients at the pediatric cardiology clinic at Ingham Medical Center in Lansing, Michigan. All of the children were affected to some extent by congenital heart disease.

Of the fifty-eight subjects thirty-two were males and twenty-six were females.

The selection process of the children involved the compilation of an exhaustive list of all clinic patients with appropriate symptomatology. Each family was then sent a letter, explaining the nature of the study and requesting their participation (see Appendix A). This letter was followed, usually within a week by a telephone call to each child's parents. Any questions they had were answered at this time and if they agreed to participate, an appointment was scheduled.

In all, 76 letters were sent to prospective subjects. Six were returned because of incorrect address. Follow-up efforts failed to locate the families. Nine families refused to participate. Two children, whose parents had consented to participate, died before they could be assessed. One other child remained too ill to allow adequate assessment. Fifty-eight subjects remained available for the study.

The subjects were divided into four groups based on their cardiac symptomatology.

Group I children (14 subjects, mean age = 30 months) had defects which resulted in left-to-right shunting of the blood within the heart. This group included cases of patent ductus arteriosus (PDA), atrial septal defects (ASD), and ventricular septal defects (VSD). Symptomatically, these children suffered from chronic congestive heart failure.

Group II children (13 subjects, mean age = 56 months) had defects resulting in right-to-left shunts including transposition of the great arteries (TGA), pulmonary atresia (PA) and tetralogy of Fallot (TOF). In addition they had histories of cyanotic or hypoxic symptoms.

Group III children (17 subjects, mean age = 42 months) had either left-to-right or right-to-left shunting defects but did not suffer from chronic congestive heart failure or excessive cyanosis.

Group IV children (14 subjects, mean age = 45 months) had insignificant heart disease. No surgical intervention had been performed and in no case was it anticipated.

The last group served as a control group of sorts in as much as each child had a heart ailment but the parents were aware that it was insignificant and would probably never become problematic or require surgery.

The process of determining the appropriate group placement for some subjects was a complicated one. Group IV subjects were readily identifiable as were some of the subjects in the other groups. A number of the children however, had multiple symptomatology. For others there was some question as to the chronicity of their symptoms.

The ultimate decision on each subject was made by the pediatric cardiologist who was directly responsible for their medical care.

Measures

Since the purpose of the study was to assess the physical, cognitive and psychomotor development of the subjects, the study directed itself toward two goals.

The first was to collect physical, social and psychological development information regarding the children. Each subject and his or her parents were seen either in their homes, or, in a few instances, in the clinic offices. In each case the parents were interviewed (see Appendix B) to gain information regarding the following:

1. Family information: Age, education and occupations of father and mother; ages, sexes and education levels of all siblings or others living in household.

2. Pregnancy period: Planned vs. unplanned; frequency of obstetrical care; hours of labor; presentation of infant--head first, feet first, breech or Caesarian; use of forceps; use of anesthesia.

3. Perinatal period: Gestational age as estimated by physician at delivery; birth weight and length; description of any complications during neonatal course; admission to neonatal intensive care unit or transfer to another hospital; number of days in hospital before going home.

4. Surgical (corrective or palliative) procedures: Catheterizations--number and age at each; surgeries--number and age at each.

5. Nursing information: Breast or bottle feeding; age at weaning.

Following the interview each subject was weighed and height and head circumference measurements were taken (see Appendix C).

Next, a battery of psychological assessments were completed. For subjects under 30 months of age Denver Developmental Screening Tests and Bayley Scales of Infant Development--Mental Scale and Motor Scale--were administered (see Appendix D).

Subjects between 30 months and 6 years were given Denver Developmental Screening Tests (see Appendix E) and Stanford-Binet Intelligence Tests (see Appendix F). Subjects over 6 years of age were given only Stanford-Binets.

The mothers of all subjects were asked to complete modified versions of the Neonatal Perception Inventory including "Average Baby," "Own Baby" and "Degree of Bother" rating scales (see Appendix G).

Statistical Analysis

After all the data were collected the following procedures were performed, using the computer program, Statistical Package for the Social Sciences.

At the outset a Pearson Correlation Coefficient Matrix was completed to allow for comparisons of each variable with each other variable in an attempt to determine any apparent relationships between variables.

Next, analysis of variance techniques were employed for the purposes of making the following comparisons:

1. Each cardiac symptom group (I-IV), was compared with each other group on all of the variables studied. Significant differences between groups were noted.

2. The subjects were then divided into new groupings based on the physical growth measurements recorded at the time of assessment. This resulted in three different weight groups, three height groups and three head circumference groups: (a) those above the 16th percentile, (b) those between the 16th and 3rd percentiles, and (c) those below the 3rd percentile. A group of children falling below the 3rd percentile on all three measurements was also formed. These groups were then compared with each other on psychological measurement variables.

3. The subjects were finally divided according to whether or not surgical repair had been performed. The post-surgical group was compared with the pre-surgical group and then those children having had surgery under hypothermic conditions were compared with the others.

The .05 level of significance was chosen to determine acceptance or rejection of each hypothesis. Results within the .10 level of significance however, were reported as approaching significance.

The next chapter will present the results of these analyses.

CHAPTER FIVE

RESULTS

In examining the results of this study each hypothesis is considered individually. In addition, an analysis of related data, as obtained through the Pearson Correlation Matrix is presented.

Hypothesis Analysis

The task in this section is to determine whether the hypotheses considered in this research should be accepted or rejected. This is not a straightforward process. The ultimate decision on each hypothesis is affected by numerous variables, and it was important to consider not only any differences between groups but also any trends or relationships between the groups that may be evident.

With regards to medical symptoms, there were definite differences between the four groups of subjects. This, of course, was arranged by design. Because of this it was possible to form a priori expectations as to the relationships between the groups. As each hypothesis was considered these were examined to see if the expectations were well founded.

> Hypothesis I: Children with serious cardiac defects tend to exhibit physical growth retardation more frequently than do less-afflicted children.

In considering this hypothesis it was first necessary to rank order the four groups according to severity of illness. Subjects in Groups I and II were considered to be the most at risk. Group I

children had histories of chronic congestive heart failure. Group II children chronically expressed cyanotic symptoms.

Group III children were considered at greater risk than the insignificantly affected subjects in Group IV but it was not possible to determine where they would fall in relation to the other groups. It seemed reasonable to expect them to perform less well than the children in Group IV, but how much so, was the question.

In effect then, hypotheses were formed about each hypothesis. For Hypothesis I they were:

1. Groups I, II and III will all rank below Group IV: the experimental groups should all express more physical delay than the control group.

2. Groups I and II will rank below Groups III and IV: the two most severely affected groups would express the most severe physical delay.

3. Group I will rank below Group II: the expectation was that the congestive heart failure group (I) should rank below the cyanotic group (II).

If all of the assumptions should prove correct, the final rank ordering of the groups would be: I, II, III, IV. If Hypothesis I were to be true, these trends should appear.

To assess the extent of growth retardation, the following variables were considered for each group: (a) weight percentile values, (b) height percentile values, and (c) head circumference percentile values. The results are presented in Table 1.

The data indicate significant differences between the groups ($p = .05$) on the variables "weight percentile" and "head circumference percentile" but not "height percentile."

Table 1

Physical Measurement Summary Table**

Group	Weight %		Height %		Head circ. %	
	$\bar{X}$	S.D.	$\bar{X}$	S.D.	$\bar{X}$	S.D.
I	16.43	15.47	34.21	29.07	35.07	27.91
II	38.77	27.25	38.92	27.19	29.31	26.02
III	41.00	25.03	38.35	30.33	51.94	27.62
IV	53.50	21.96	53.07	27.51	59.36	20.99
Totals	37.59	22.29	41.03	27.91	44.59	25.19
F ratio	6.38*		1.16		4.12*	
df	3/54		3/54		3/54	

* indicates significance at .05 level.
** complete results can be found in Appendix H, Table 13.

For the purpose of examining the trends, the results of the "physical measurement" variables are presented graphically in Figure 2.

The results of the variable "weight percentile" completely supported the projected trend: I, II, III, IV. In addition, the differences between the groups were statistically significant ($p = .05$).

The results on the variable "height percentile" partially supported the projected trend. Group I ranks below the other three, but the differences between Groups II and III were essentially non-existant. As was expected, the control group subjects (Group IV) ranked well above those in the other three groups.

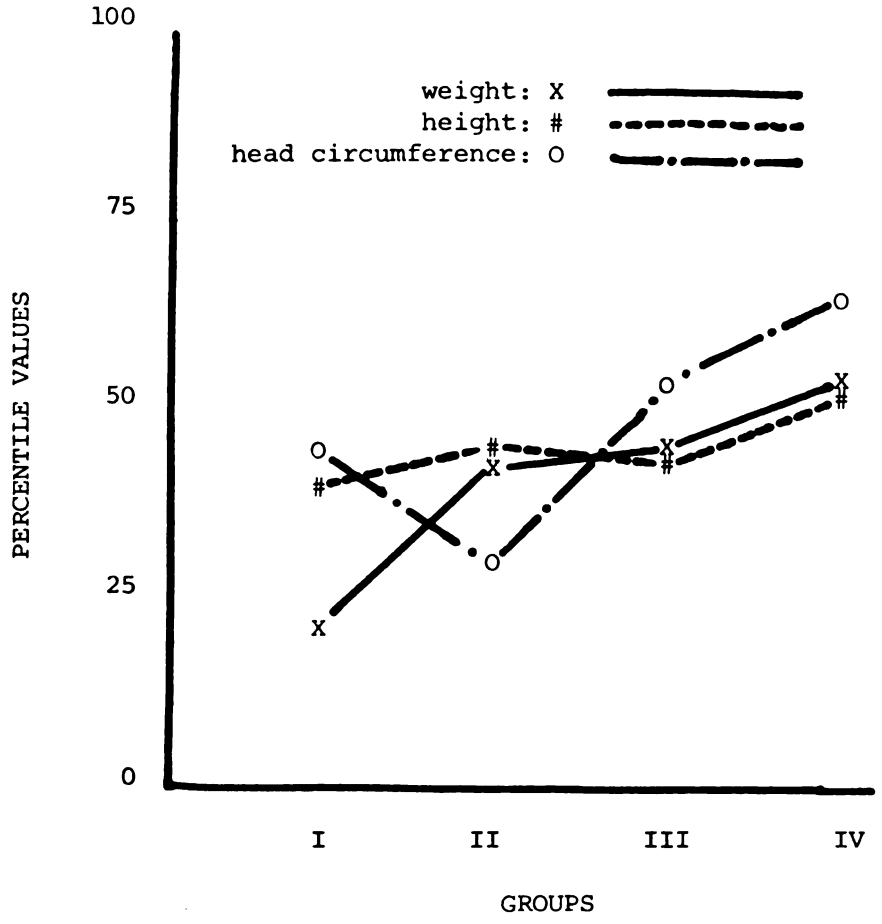

Figure 2: Mean growth percentile values presented graphically in order of projected trends (I, II, III, IV).

On the variable "head circumference percentile," the trend was once again partially supported. All three experimental groups ranked below the control and the two most severely affected groups ranked lowest of all. Group I however, ranked above Group II.

The results of this study did not completely support the projected trends. One reason for this may have been discrepancy between the mean ages of the groups, especially between Groups I and II (2:11 and 5:01, respectively).

It is reasonable to expect weight discrepancies to be most apparent in younger children and head circumference discrepancies to be most apparent in older children. Neonatal information collected on all of the groups (see Appendix H, Table 11) revealed no significant differences between any of the groups on the variables "birth weight" or "birth length." Therefore, it can be concluded that the subjects were born with essentially similar physical or biological characteristics.

A normal, healthy infant would quickly begin to gain weight. Conversely, a child at risk, such as a child with a heart ailment with symptoms apparent in the newborn period, may instead, lose weight or at least not gain significantly for an extended period of time. This might continue until medication or surgical intervention could be used to help bring the symptoms under control. As these children get older, these weight delays may disappear or at least become less significant.

Unlike weight, head size is not immediately affected by early and severe symptomatology, at least not to the same extent. An infant's head will not perceptibly decrease in size. It may, however, not grow at the expected rate and many months or even years of deprivation might occur before a child's head size is significantly smaller than his peers.

The conclusion one might draw from this then, is that, were the children in Group I older, their head sizes might be comparitively smaller, more closely resembling the children in Group II.

On the basis of this data, Hypothesis I cannot be accepted. Some significant differences were observed, and for the most part,

the expected trend was in evidence, but further study in this area is warranted. A study of more children, of similar ages, followed over a longer time period would perhaps provide more conclusive results.

> Hypothesis II: Children with serious cardiac defects tend to exhibit lags in cognitive development more frequently than do less-afflicted children.

As with the first hypothesis, the same trends were expected to appear with regard to Hypothesis II. Once again, it was anticipated that the experimental groups (I, II, III) would all rank lower than the control group. Groups I and II were expected to rank lower than Groups III and IV and Group I was expected to rank lowest of all, resulting in an overall expected order of I, II, III, IV. If Hypothesis II were to be acceptable, these trends should appear.

In considering Hypothesis II, the following variables were used: the "Denver Developmental Screening Test" (DDST); the "Bayley Scales of Infant Development--Mental Development Index" (BSIDMDI); and the "Stanford-Binet Intelligence Quotient" (SBIQ).

The actual results are summarized in Table 2. There were no significant differences between the groups on any of the variables.

Figure 3 provides a graphical illustration of the results. From it the presence or absence of the anticipated trends can be observed.

On the variable "Denver Developmental Screening Test" an ascending linear relationship between the groups was evident. This result supports the anticipated trend.

While the relationship between the groups on the "Bayley Mental Scale" was somewhat less linear, the expected trend was nevertheless, observed. Only minimal differences were found between Groups II and III but Group II ranked lower.

Table 2

Psychological Assessment Summary Table*

Group	DDST**		BSIDMDI		SBIQ	
	$\bar{X}$	S.D.	$\bar{X}$	S.D.	$\bar{X}$	S.D.
I	2.36	0.74	94.00	15.59	88.57	17.41
II	2.43	0.53	99.83	10.50	93.86	4.78
III	2.44	0.81	100.20	27.15	91.00	13.40
IV	2.83	0.39	108.33	21.36	97.36	11.91
Totals	2.51	0.65	99.19	17.13	92.97	12.19
F ratio	1.25		0.43		0.82	
df	3/45		3/17		3/33	

* complete results can be found in Appendix H, Table 14.
** for purposes of computation Denver scores were given numerical values as follows: Normal = 3, Questionable = 2, Abnormal = 1.

Finally, when the groups were compared on the basis of the "Stanford-Binet" scores, the trend was only partially supported. Group I ranked lowest and Group IV ranked highest, but Group III ranked below Group II.

Once again, the differences in age may partly explain this difference. To a certain extent the findings suggested that the detrimental effects of cardiac illness on ultimate psychological development disipate with age, allowing for a sort of "catch-up" phenomenon.

The trend analysis of these variables lends little support however, to Hypothesis II. The absence of significant differences between the groups requires that Hypothesis II be rejected on the basis of these data.

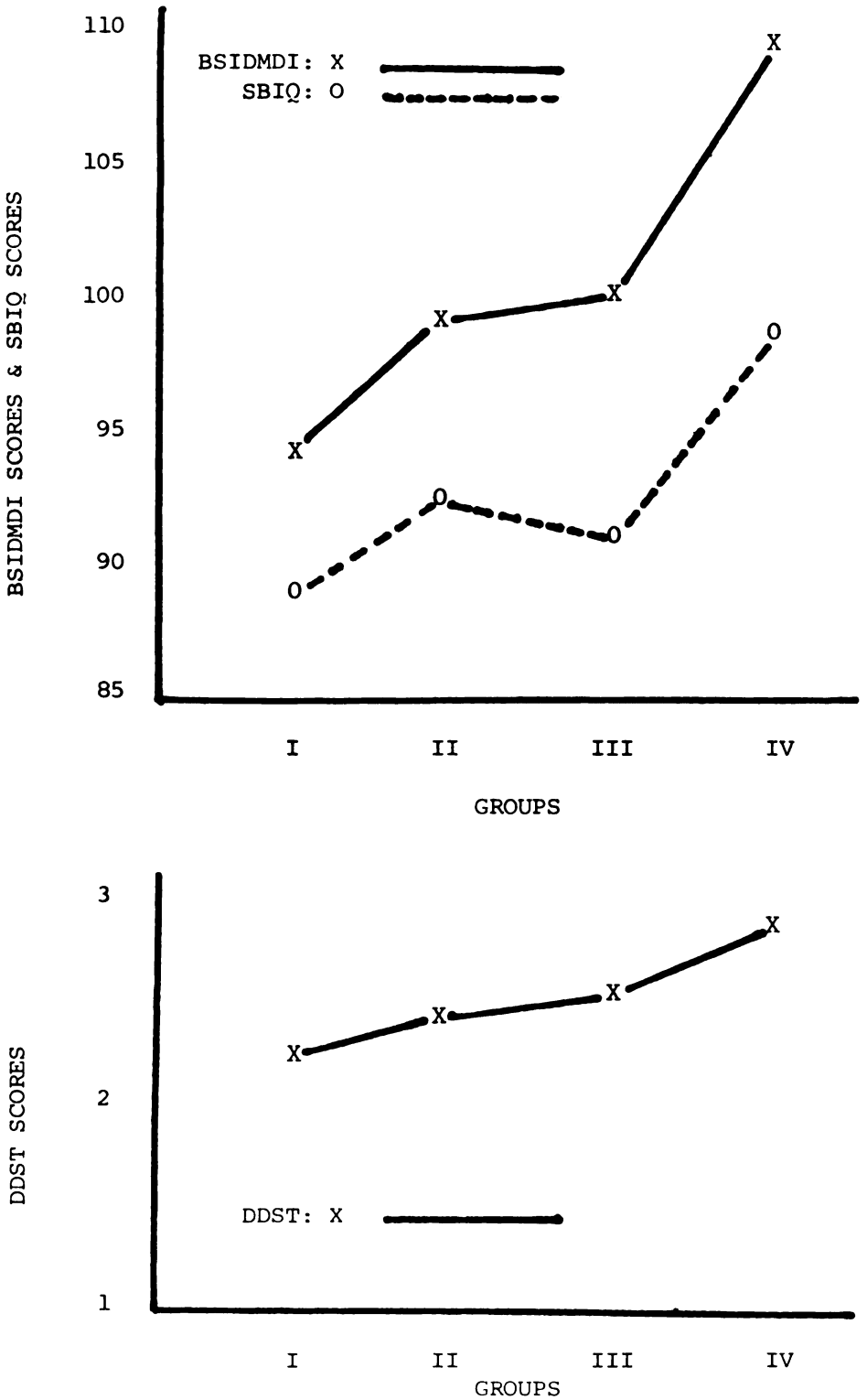

Figure 3: Mean values for cognitive psychological assessment variables presented graphically in order of projected trends (I, II, III, IV).

In future research in this area, it may be more productive to employ an item analysis of the items included in each of the scales. It may then be possible to determine whether particular areas such as language development, fine motor development, eye-hand coordination, etc., are more affected than other areas. When the scales are viewed in their entirety it is difficult to make any specific interpretations. An item analysis may allow for this.

> Hypothesis III: Children with serious cardiac defects tend to exhibit lags in motor development more frequently than do less-afflicted children.

Only one variable was available for use in considering Hypothesis III and that is the "Bayley Scales of Infant Development--Psychomotor Development Index" (BSIDPDI). To a certain extent, this was a hinderance because only data on subjects younger than 30 months of age could be included since children older than 30 months were, instead, assessed using the Stanford-Binet.

As with the first two hypotheses, the same trends and the same ultimate rank ordering (I, II, III, IV) were anticipated. The actual results are reported in Table 3.

A significant difference between the groups did not occur. A graphical illustration of the results (see Figure 4) indicate that the anticipated trend was only partly in evidence.

Groups I and II ranked far below the other two groups but subjects in Group III appeared to be completely unaffected by the limitations of their medical conditions. This data should be considered very weak, however, since the number of subjects included from each group was very small (Group I = 7, Group II = 6, Group III = 5, and Group IV = 3), especially Group IV.

Table 3

Psychomotor Assessment Summary Table**

Grp. / Var.	I Mean S.D.	II Mean S.D.	III Mean S.D.	IV Mean S.D.	Totals
BSIDPDI	83.00 16.97	85.67 18.91	105.40 23.19	98.00 10.00	91.24 17.13
					1.74 F ratio 3/17 df

** complete results can be found in Appendix H, Table 14.

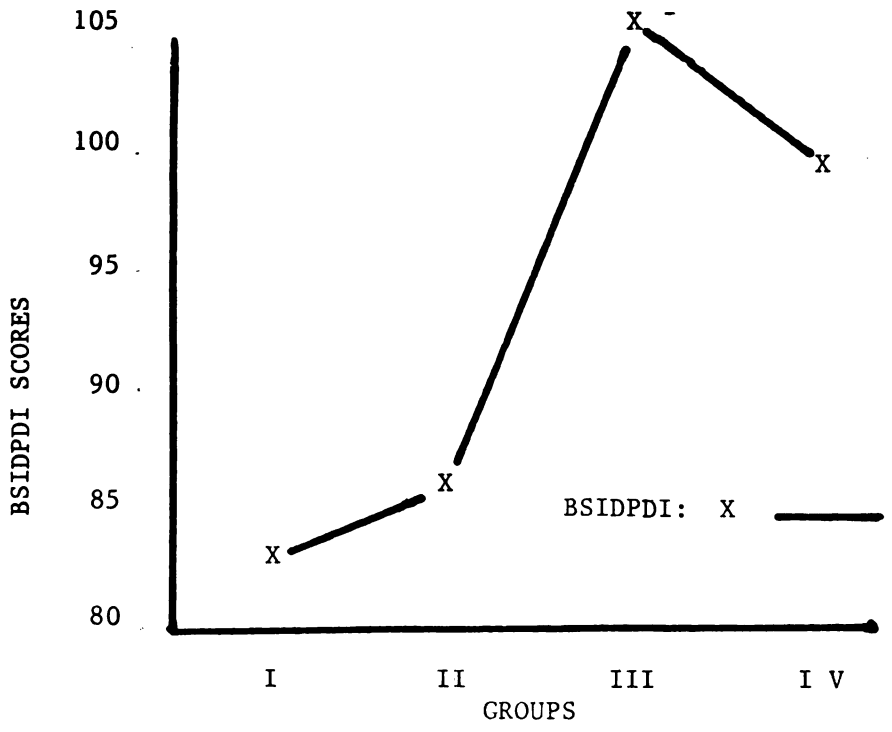

Figure 4: Mean values for psychomotor assessment variable (BSIDPDI) presented graphically in order of projected trends (I, II, III, IV).

Once again the results were very inconclusive. One observation does seem rather clear though, and that is that severely affected infants, expressing chronic symptoms, are severely limited in their psychomotor development. This is not surprising given their physical conditions.

Based on these data, Hypothesis III must be rejected. The data suggested that severely afflicted children are delayed in their psychomotor development. However, there was a wide range of variation among children who were less ill. As in the previous instances, further research seems warranted.

> Hypothesis IV: Children with cardiac defects who do express growth failure will similarly tend to lag in cognitive and motor function development.

A consideration of this hypothesis required a regrouping of the subjects along new independend variables; namely, growth measurement variables. To accomplish this, each subject was categorized according to his percentile score into a weight, height and head circumference percentile group. In addition a "failure-to-thrive" group was also formed to examine the effects of multiple physical retardation. This reorganization resulted in the following groups:

W-I - all subjects above the 16th percentile for weight.
W-II - all subjects at or below the 16th percentile and above the 3rd percentile for weight.
W-III - all subjects at or below the 3rd percentile for weight.

H-I - all subjects above the 16th percentile for height.
H-II - all subjects at or below the 16th percentile and above the 3rd percentile for height.
H-III - all subjects at or below the 3rd percentile for height.

HC-I - all subjects above the 16th percentile for head circumference.
HC-II - all subjects at or below the 16th percentile and above the 3rd percentile for head circumference.
HC-III - all subjects at or below the 3rd percentile for head circumference.

F-I - all subjects above the 16th percentile for height, weight and head circumference.
F-III - all subjects at or below the 3rd percentile for height, weight and head circumference.

(No F-II group was formed because no children fell between the 16th and 3rd percentiles on all three variables. See Appendix I for complete tables and group N's.)

The 16th percentile represented one standard deviation from the mean. The 3rd percentile represented two standard deviations from the mean.

As with the previous hypotheses, trends were anticipated. It was expected that the highest percentile group in each category would rank well above the two lower percentile groups. Subsequently, it was anticipated that the mid-range group would perform better than the lowest group in each category.

In considering this hypothesis, mean scores on the following variables were used: DDST, BSIDMDI, BSIDPDI, SBIQ. A summary of significant correlations is provided in Table 4, and graphical illustration of the results are presented in Figures 5-8.

With regard to the weight percentile variable, the trend on the Denver was in evidence and a linear relationship was observed. In addition, the differences between the scores were significant ($F = 3.62$, $p = .05$).

With regard to height percentile values, although the relationship on the Denver was curvilinear, the trend was in evidence. Once again the differences were significant ($F = 6.01$, $p = .01$).

Table 4

Significant Correlations Between Physical and Psychological Measurements

Variables			r	N	p
Weight percentile	X	DDST	0.3535	49	0.013
Weight percentile	X	BSIDMDI	0.4632	21	0.034
Weight percentile	X	BSIDPDI	0.6922	21	0.001
Height percentile	X	DDST	0.3400	49	0.017
Height percentile	X	BSIDMDI	0.4914	21	0.024
Height percentile	X	BSIDPDI	0.6817	21	0.001
Height percentile	X	SBIQ	0.3906	37	0.017
Head circumference percentile	X	BSIDMDI	0.4887	21	0.025
Head circumference percentile	X	BSIDPDI	0.6506	21	0.001

When head circumference percentile values were considered on the Denver, though, the trend was not supported. Only minimal differences were observed between any of the groups.

Finally, when the two "failure-to-thrive" groups were contrasted, although the differences were short of significant, the anticipated directional relationship was observed.

On the Bayley Mental Scale variable, the weight percentile relationship presented as curvilinear, with only minimal differences between Groups I and II. The anticipated trend was observed, however.

With regard to height percentile values on this variable, though, the trend was only partially in evidence. The number of subjects in the two "delayed" groups was small. Both ranked well below the "normal" group but the mid-range group also ranked below the lowest percentile group. The differences between the groups were significant ($F = 3.18$, $p = .10$).

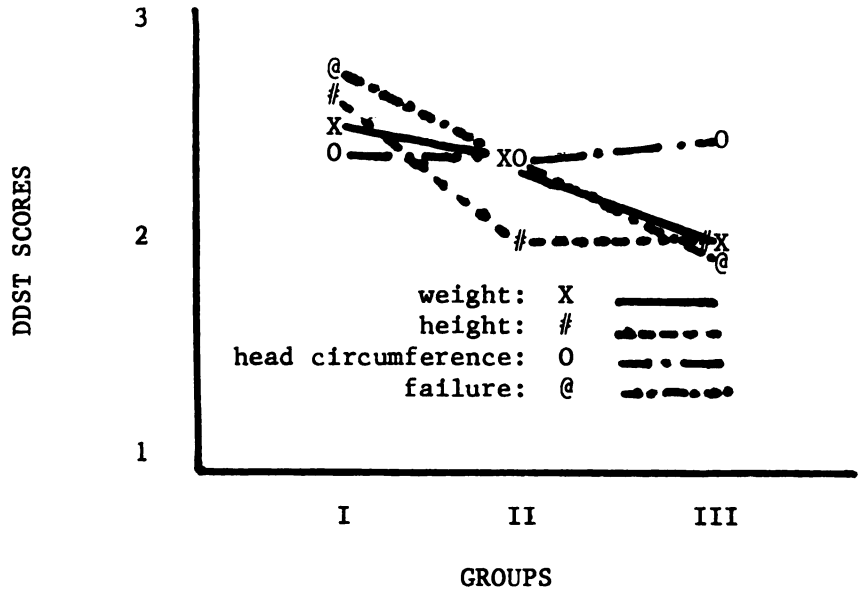

Figure 5: Growth percentile groups--graphical illustration of mean scores on the Denver Developmental Screening Test.

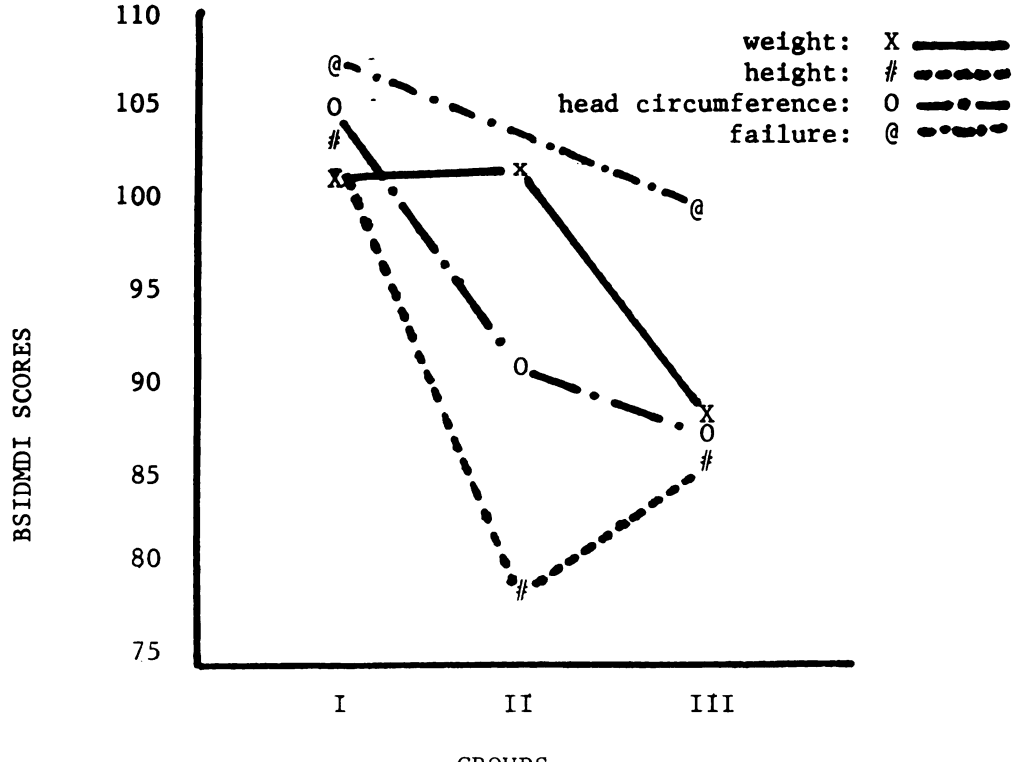

Figure 6: Growth percentile groups--graphical illustration of mean scores on Bayley Scales of Infant Development--Mental Scale.

SB IQ SCORES

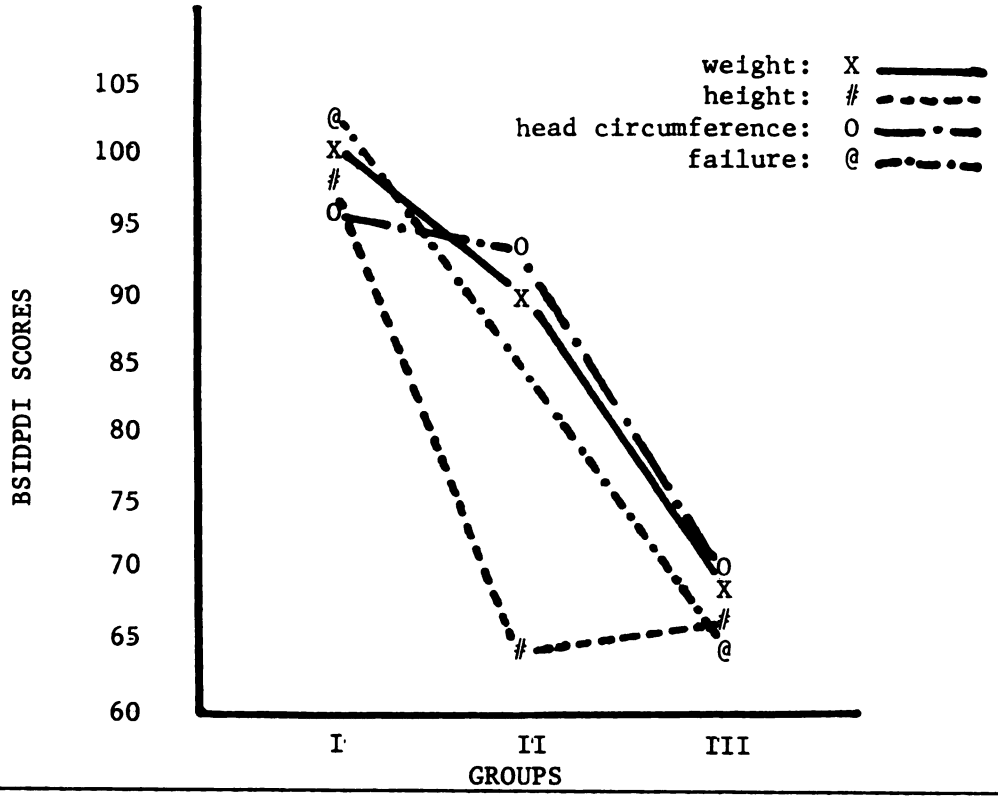

Figure 7: Growth percentile groups--graphical illustration of mean scores on Bayley Scales of Infant Development--Motor Scale.

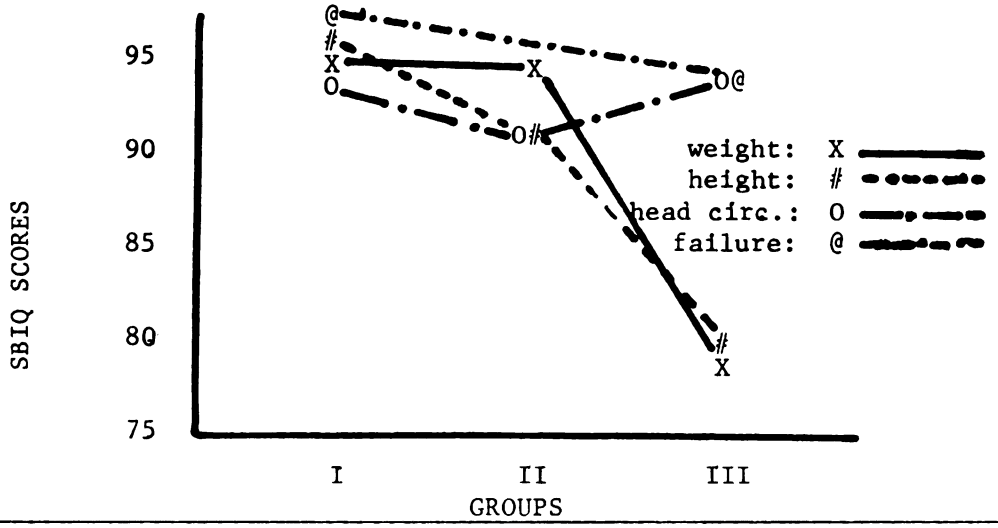

Figure 8: Growth percentile groups--graphical illustration of mean scores on the Stanford-Binet Intelligence Test.

When head circumference percentile groups were considered on this variable, the trend was again observed and the relationship became more linear. Group differences were not significant, however.

Finally, when the "failure" groups were contrasted on this variable the trend was again in evidence but the group differences were minimal.

Psychomotor development, as measured by the Bayley Motor Scale, was perhaps the variable which was most severely affected by growth retardation in every category. There were marked and significant differences in every instance: Weight % - $F = 9.32$, $p = .01$; Height % - $F = 10.08$, $p = .01$; Head circ. % - $F = 4.34$, $p = .05$; Failure group % - $F = 11.59$, $p = .01$.

The anticipated trend was observed and the relationships were linear in every instance except "height percentile" where it was curvilinear.

The effects of growth failure on Stanford-Binet IQ scores was less conclusive than with the previously mentioned psychological measures. The expected trend was observed with regard to both weight and height percentile values and the differences with these were significant for height and approached significance for weight. (Height: $F = 4.99$, $p = .05$; Weight: $F = 2.93$, $p = .10$).

However, only minimal differences between groups were observed with regard to both head circumference percentile and multiple growth failure percentile values.

With regard to the correlation analysis, the only measurement variable that correlated strongly with the Stanford-Binet was height percentile. The data in Table 4 suggest that growth retardation affects development in a younger child more extensively than in an

older child. This may be indicative of a "catch-up" phenomenom, where, even though growth retardation may persist, it does not continue to detrimentally affect a child's development.

In terms of weight and height retardation then, the effects on psychological development are severe and in evidence. Both mental and motor development showed retardation in the most delayed group.

In the mid-range group, the results were less similar. Younger children were more affected by height retardation in both the mid-range and the lowest percentile groups as evidenced by performance on both of the Bayley scales. Weight retardation in infancy though, was less detrimental unless it was very severe and then motor function was more severely affected than cognitive development.

In older children, severe weight and height retardation both had detrimental effects on psychological functioning, as evidenced by scores on the Stanford-Binet. Scores obtained by the mid-range group though, were essentially the same as those obtained by the normal growth groups.

As far as small head size was concerned, if a child fell below his peers as an infant it appears to have had a negative effect on his psychological development, especially if the lag was severe. For older children with small head circumferences, though, there were almost no differences between their scores on both the Denver and the Stanford-Binet and the scores of their normal peers.

To summarize, it must be said that the results of this analysis were inconclusive. Many significant differences were found and the anticipated trends were much in evidence. The small number of subjects available through this study make it hazardous to either accept or

reject the hypothesis. The findings of this research lean toward supporting the hypothesis but, as with the previous hypotheses, further research is called for.

> Hypothesis V: Profound hypothermia techniques employed at the time of surgery do not adversely affect the child.

In considering this hypothesis, the results from the "surgery -vs.- non-surgery" and "surgery before one year of age -vs.- no surgery before one year of age" groupings (see Appendicies J and K) were used to make the necessary comparisons. The data indicated no significant or even near-significant differences between any of the groups. This was the case when considered on both physical and psychological variables.

Based on this study, there is no reason to reject the hypothesis. It must be remembered though, that the sample size in this comparison is small, only 11 children were operated on using hypothermic techniques. While it is encouraging that they exhibited no differences from their peers, it would seem advisable to continue to follow these children as well as to assess many more who may undergo similar surgeries in an effort to provide more support to the belief that there are no detrimental effects from this surgical practice.

Analysis of Related Data

As was stated in Chapter 4, a Pearson Correlation Coefficient Matrix was computed correlating all of the variables with all of the other variables. In all, 44 variables were included, resulting in 1,892 correlations being computed.

Whenever this kind of a procedure is used the probability of committing a type I error is increased simply because when the number of correlations is increased, the number of them that will appear significant simply because of chance also increases. This, then, is a disadvantage to using this technique.

On the other hand, computing a correlation matrix also affords some advantages. Some variables may, in fact, correlate strongly with one another but because such a correlation was not anticipated or looked for in the design, the relationship between the variables may be overlooked. When a matrix is computed however, such relationships are revealed. Space does not allow for the printing of the entire matrix, nor is it necessary to do so. It is also not necessary to report all of the significant correlations that appeared simply because many variables correlate with each other for obvious reasons. For example, it is logical to expect "birth weight" to correlate strongly with "birth length." Similarly one would expect "mother's age" to correlate strongly with "father's age." In both cases they did.

In this section only those correlations which were significant and which represent relationships between variables that were not necessarily anticipated will be reported.

An interesting correlation occured between the weight and head circumference percentile variables and the expectation of future catheterization and surgery. These relationships are reported in Table 5.

These data seem to suggest that growth retardation persists in presurgical or uncorrected cases. Conversely, they seem to suggest that post-surgical children achieve normal growth patterns.

Table 5

Significant Correlations Between Growth Retardation and Future Catheterization and Surgery

Variables			r	N	p
Weight percentile	X	future cath.	-0.2703	58	0.040
Weight percentile	X	future surg.	-0.2976	58	0.023
Head circumference percentile	X	future cath.	-0.2884	58	0.028
Head circumference percentile	X	future surg.	-0.3619	58	0.005

In the next table (Table 6) some of the neonatal period variables are correlated with future performance on psychological tests. Birth weight is correlated with both scales from the Bayley. Whether or not a child required admission to an intensive care unit (NICU) at birth is correlated with his ultimate performance on the Denver, the Bayley Motor Scale and the Stanford-Binet. Total number of days in the hospital before going home after birth is correlated with both the Denver and the Stanford-Binet. Finally, whether or not the child had to be transported to a different hospital during the newborn period is correlated with his ultimate performance on the Denver, the Bayley Motor Scale and the Stanford-Binet.

The data suggest that larger newborns ultimately perform better on the Bayley Infant Scales. Conversely, babies in trouble at birth, who require special care, remain in the hospital longer or need to be transported to another hospital (and are therefore separated from their mothers), do poorly when subsequently assessed with the Denver, the Stanford-Binet or the Bayley Motor Scale. It is interesting that these experiences do not seem to affect performance on the Bayley Mental Scale.

Table 6

Significant Correlations Between Neonatal Variables and Subsequent Performance on Psychological Tests

Variables			r	N	p
Birth weight	X	BSIDMDI	0.5987	21	0.004
Birth weight	X	BSIDPDI	0.6200	21	0.003
NICU	X	DDST	-0.4984	49	0.001
NICU	X	BSIDPDI	-0.5891	21	0.005
NICU	X	SBIQ	-0.4305	37	0.008
Days in hospital	X	DDST	-0.3556	49	0.012
Days in hospital	X	SBIQ	-0.5238	37	0.001
Transport	X	DDST	-0.3753	49	0.008
Transport	X	BSIDPDI	-0.6280	21	0.002
Transport	X	SBIQ	-0.3927	37	0.016

In another comparison, breast-fed babies differed significantly from bottle fed babies in some surprising ways (see Table 7).

Table 7

Breast-feeding as a Function of Brithweight and its Effects on Future Performance on Psychological Tests

Variables			r	N	p
Breast-fed	X	Birthweight	0.2813	58	0.032
Breast-fed	X	DDST	0.3257	49	0.022
Breast-fed	X	BSIDPDI	0.5137	21	0.017

The breast-fed babies performed better on both the Denver and the Bayley Motor Scale. The data also seem to suggest that babies who are larger at birth are more likely to be breast-fed. This finding may be a function of the fact that many babies who are small at birth require longer hospitalizations and may even be admitted to intensive care

units or special care nurseries. These occurrances result in more extensive separations from their mothers during the first several days and as a result of these separations, bottle feeding may be employed to make the situations easier.

In another relationship, the responses of mothers to the "Own Baby" rating scale in the Neonatal Perception Inventory (see Appendix G) correlated strongly with a number of variables (see Table 8).

Table 8

Significant Relationships Between Mother's Responses to the "Own Baby" Rating Scale and Her Child's Surgical History, Her Husband's Education and Her Own Employment

Variables			r	N	p
NPI-OWN	X	Catheterization	0.2827	55	0.037
NPI-OWN	X	Surgery	0.3457	55	0.010
NPI-OWN	X	Total surgeries to date	0.3394	33	0.011
NPI-OWN	X	Father's education	-0.2949	54	0.030
NPI-OWN	X	Mother's employment	-0.3352	55	0.012

Table 8 indicates that mothers whose children had had catheterizations or surgeries saw those children as being more difficult to care for. Conversely, those women who were employed or whose husbands had good educations, did not see their children as being difficult to care for.

Finally, the data provided some interesting information about planned -vs.- unplanned pregnancies (see Table 9).

The educational levels of the parents and the occupations of the fathers correlated directly with planned pregnancies.

Table 9

Significant Correlations Between Planned Pregnancies and Parent's Educational Level and Father's Occupation

Variables			r	N	p
Planned pregnancy	X	Mother's educ.	0.3494	57	0.008
Planned pregnancy	X	Father's educ.	0.2572	54	0.060
Planned pregnancy	X	Father's occ.	0.3407	55	0.011

CHAPTER SIX

DISCUSSION

In this chapter the results of this research are summarized and discussed, the limitations encountered are noted, and recommendations for future research are given.

Summary of Results

This study was undertaken with two goals in mind: (a) to collect background and developmental information about the children, and (b) to formally assess them along physical, cognitive and motor development indicies. An overriding question to be answered was whether or not children expressing certain symptoms were more inclined to developmental delays than less symptomatic children.

Although this trend was observed the results of this study were not significant. The evidence did not support a contention that children who chronically suffer congestive heart failure or who are chronically cyanotic are at greater risk, developmentally, than their less-afflicted peers.

The first three hypotheses all addressed this issue. Hypothesis I was concerned with the physical development of chronically ill cardiac children. Although children suffering chronic congestive heart failure did tend to be underweight, the pattern did not hold for height or head circumference.

Hypothesis II considered the cognitive development of the children. There were no significant differences between any of the groups.

Hypothesis III was concerned with the psychomotor development of the subjects. In this instance, significant results once again were not observed but the suspected trend was in evidence.

Although the results of this study do not support the theory of developmental delay secondary to medical severity, they do suggest that, regardless of actual symptomatology, a child who does exhibit lags in physical development is a much greater risk for also experiencing delays in cognitive and psychomotor functioning as well.

This was supported by the results concerning Hypothesis IV. The children were grouped according to growth percentile measurements. Regardless of medical sypmtoms, if a child were undergrown, he was grouped with peers expressing similar growth patterns. When physical size was correlated with cognitive and psychomotor development the relationship was positive and significant. Physical delay correlated strongly with psychological delay and, conversely, physical maturity correlated strongly with psychological maturity.

Hypothesis V considered the effects of profound hypothermic surgical procedures on the physical and psychological development of children who had undergone such techniques. The data of this study revealed no differences between these children and children operated on without the use of hypothermia.

Limitations of Study

The major problem which has affected this study since its inception has been that of attaining an adequate and representative sample of cardiac children.

The ages of the children in this study covered a wide range (five months to eleven years). When a child has a heart defect, both the cardiologist and the thoracic surgeon, in considering the best methods of treatment, are always competing against time. Some of the most carefully planned surgical procedures are never performed because, for the patient, time unexpectedly runs out. In the past decade and especially in the past 4-5 years, the sophistication of surgical procedures has greatly increased. Intervention is now possible at earlier and earlier ages. However, the unexpected still occurs.

Because of this natural attrition, any researcher studying children with heart defects must be cognizant of the effect this factor will have on the sample. Children at the older end of the spectrum are the ones who have survived. If they or their peers had been studied when they were infants and toddlers, their numbers would have been greater and the results probably would have been different. Included in such a sample would have been the very ill children who have not survived. And, because of the severity of their defects, they probably would have been more likely to express both physical and psychological delays.

Many studies mentioned in Chapter 3 report improvements in subjects with age. These same studies though, do not provide information about subjects who may have died between assessment periods. It would not be unreasonable to assume that these were many of the subjects who performed most poorly or who were physically, most retarded.

After subjects were assigned to their respective groups in this study the same kind of problem existed. Large age differences existed between the groups, especially between Groups I and II.

Additionally, since the potential subject pool was so small (letters were sent to the parents of every child who qualified), it was not possible to randomly select some subjects and not others; nor was it possible to match the subjects from one group to another.

Another problem that was never able to be solved was that of determining the severity of illness of each of the subjects, even within each group. Compared to another group of children with histories of chronic congestive heart failure it is hard to say how Group I in this study would match up. Because these children had not been assessed in this way since birth, it was not possible to know about the quantitative and qualitative aspects of their episodes of congestive failure. Would they be similar or different to another sample drawn from another clinic? This same question must be asked for the other three groups as well.

Another problem encountered in this study was the method in which data was collected. At the outset, the decision was made to visit the children and their parents in their homes. This made it more convenient for many of the families, especially those who lived great distances from the Lansing area. In fact, many parents agreed to participate only after they were told that a home visit would be made. The problem however, was that this made it more difficult to accurately assess the children, especially on physical measures. Instead of the very sophisticated scale in the clinic, a bathroom scale had to be used and, although the same scale was used for each child, it was not possible to be completely accurate. Similarly it was difficult to accurately procure height and head circumference measurements. In clinic, a child can be laid on a paper covered table and lines can be

drawn at his head and his feet. When he is removed it is a simple matter to measure the distance between the marks. In a kitchen or a living room though, even with mother's assistance it is difficult to convince a reluctant child to stand up straight or to hold still while his head circumference is measured.

Additional problems existed with some of the psychological instruments that were used. Because of the small number of subjects available and the resulting wide age range, it was necessary to use different tests depending upon the child's age. Correlations between the scales (Denver, Bayley and Stanford-Binet) are too weak to permit them to be combined for purposes of comparisons. The result was that each group, already small, had to be sub-divided depending upon the tests used for each child. If larger groups had been available, and if the ages of the children within each group had been similar, one test could have been given to all and an item analysis could have been completed allowing for more sophisticated comparisons than were possible with only scaled scores avaiable.

Recommendations for Future Research

Although this research did not result in many significant findings, and although, for the most part, the hypotheses were unsupported, to a large extent the expected trends were in evidence, enough so that future research seems warranted.

A study could be designed to follow patients from many clinics over a period of several years. A subject could enter the study at birth or as soon as a defect was diagnosed. His progress could be closely measured; growth curves could be plotted and episodes of

failure or cyanosis could be noted. Such an approach would permit the cardiologists involved to more specifically group the subjects according to the severity of their illness.

Different time periods that may be critical for development could also be studied using this approach. Is it more detrimental for a child to be in failure during the first few months of life or is it more problematic if it occurs during the latter half of the first year?

A long term study would also allow for the effects of surgery at different ages to be studied.

While it would seem advisable to collect the physical and psychological assessment data in the setting of the clinic, it would nevertheless be beneficial to visit the child at his home periodically. These visits could be conducted by a social worker or a public health nurse and would permit an assessment of environmental factors which may effect the child's development. The parents of each subject could be interviewed and information about the pregnancy and neonatal periods could be obtained.

Finally, it should be emphasized that the true value of any research study lies in the ultimate beneficial effects it might have on future treatment or intervention. Should a research project, such as the one being proposed here, be conducted, it would be important to provide remedial supports and special services to any of the children and families for whom it might be warrented. Special programs to provide physical and psychological stimulation to delayed children could be developed. Supportive, therapeutic programs for parents and families could also be offered, especially to help them better understand their child's defect and to help them prepare their child for catheterization and/or surgery, as the need arises.

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APPENDICES

APPENDIX A

LETTER OF EXPLANATION

AND ACKNOWLEDGEMENT OF PARTICIPATION FORMS

Dear

We are writing to request your assistance in a project we are undertaking to help us learn more about the way in which children with heart defects grow and develop. It is our hope that this knowledge will better enable us to care for your child and for the other children we see at the clinic, both now and in the future.

As you may or may not know, some children with heart problems grow more slowly, physically, than do children who are not affected. Sometimes, even children with similar defects grow at very different rates.

While we know this about physical growth, we do not know very much about the psychological development of children with heart disease.

As you know from watching your own children, the preschool years are filled with learning as a child encounters his environment. Each new touch, taste and smell is another source of learning. As a child's muscles grow and develop he acquires greater motor abilities that enable him to sit, crawl, walk and run with progressive ease. All of this prepares him for his entry into the childhood years.

Just as physical development varies from child to child, so too, does the rate of cognitive and motor development. The more we can learn about a child's development, the better equipped we are to assist that child's parents in providing him with experiences and even exercises that can help him develop optimally. We want to learn as much as we can about your child and children like him so that we can better assist all parents of children with heart defects as they help their children grow.

To do this, a research project has been planned. In the course of this project we hope to interview you and many other parents. During this interview we will be asking you questions about your family, your child, and about his development.

In all, we will need about 2½ - 3 hours of your's and your child's time. There will, of course, be no charge for your participation.

After we have completed our assessment of your child we will be happy to answer any questions you may have. With your permission, the results of your child's assessment will become a part of his clinic record so that we may continue to refer to it as we provide you with care.

While we do hope to publish the results of our study, complete confidentiality and anonimity will be rigidly maintained. If names are used in the report, they will be fictitious names. Furthermore, any information about a child or his family will be presented in such a way that it will not be possible for anyone other than perhaps the professional clinic staff, to identify them.

We hope to be able to complete this project by the end of September. Whenever possible we will combine your child's assessment with a visit to the clinic. Or, if it is more convenient, and with your permission, Mr. Tom Taflan-Barrett, a doctoral candidate in psychology at Michigan State University, will come to your home for an appointment and gather the necessary data. In this way we hope to be able to see all of the children by the end of the summer.

If you are interested and willing to participate, please sign the attached permission form and return it to us in the stamped envelope that is provided. Since you may have questions you would like answered before agreeing to participate, Mr. Barrett will be calling you within a few days of your receiving this letter. At that time he will answer your questions, and if you wish to participate, schedule an appointment with you.

Thank you very much for your time and consideration.

Sincerely,

Albert W. Sparrow, M. D.

Thomas F. Taflan-Barrett, M. A.

Cardiac Developmental Assessment Project

Acknowledgement of Participation

I have read the attached explanatory letter requesting my participation and the participation of my child in the developmental research project being conducted under the auspices of Dr. A. W. Sparrow and the cardiac clinic at Ingham Medical Center.

The study has been explained to me and I understand the explanation that has been given and what my participation and my child's will involve.

I understand that I am free to discontinue my participation in the study at any time without penalty

I understand that the results of the study will be treated in strict confidence and that I will remain anonymous. Within these restrictions, results of the study will be made available to me at my request.

I understand that my participation in the study does not guarantee any beneficial results to me.

I understand that, at my request, I can receive additional explanation of the study after my participation is completed.

It is with this knowledge and these assurances that we agree to participate.

father's signature_____ date_____

mother's signature_____ date_____

witness signature_____ date_____

(please ask a neighbor or someone other than a member of your immediate family to witness your signature).

child's name_____

child's birthdate_____

APPENDIX B

DATA COLLECTION FORM

Cardiac Developmental Assessment Project

Information Form

Code No. _____ Wt. _____ % _____

Group _____ Sex _____ Ht. _____ % _____

h.c._____ % _____

N.P.I.:_____ DDST:_____

Degree of Bother: _____ BSID: MDI_____

PDI_____

S-B: IQ _____

I. Family - Socio-economic factors -

Father age_____ Mother age_____

education_____ education_____

occupation_____ occupation_____

Sibblings and others in household

age	sex	education	occupation	at home

II. Pregnancy -

1). planned vs. unplanned _____

2). did mother receive obstetrical care? _____

3). at what point during pregnancy did care begin? _____

4). estimated number of obstetrical visits? _____

5). frequency of visits? _____

III. Labor and Delivery -

1). length of labor? _____

2). type of delivery: head, feet, breech, Caesarian? _____

3). were forceps used? _____

4). was mother anesthesized? _____

kind? _____ dosage? _____

IV. Neonatal Period -

1). gestational age as estimated by physician at delivery?_____

2). birth weight? _____

3). length at birth? _____

4). Apgar scores: one minute? _____

five minutes? _____

5). was oxygen required at time of delivery or during stay in hospital and to what extent? _____

_____

6). were other supportive procedures required and to what extent? _____

_____

_____

7). was the baby admitted to the NICU? _____

8). length of hospital stay before going home? _____

9). was baby transported to another hospital? _____

V. Neo - parent Information -

1). how frequently did parents visit child: frequently, often, seldom, rarely? parents - _____

hospital record - _____

2). are there any nursing notes or social service observations which are pertinent or speak to the duration or quality of parental interaction with baby? _____

_____

_____

VI. Surgical (corrective and/or palliative) procedures -

1) Date Procedure Hypothermia Time in hosp.

_____

_____

_____

_____

_____

2). are future procedures planned and for when? _____

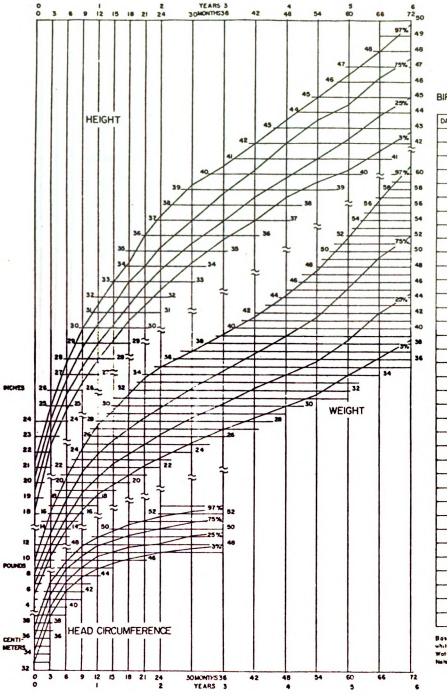
_____

_____

APPENDIX C

GROWTH CHARTS

GROWTH CHART
BOYS 0-6 YEARS

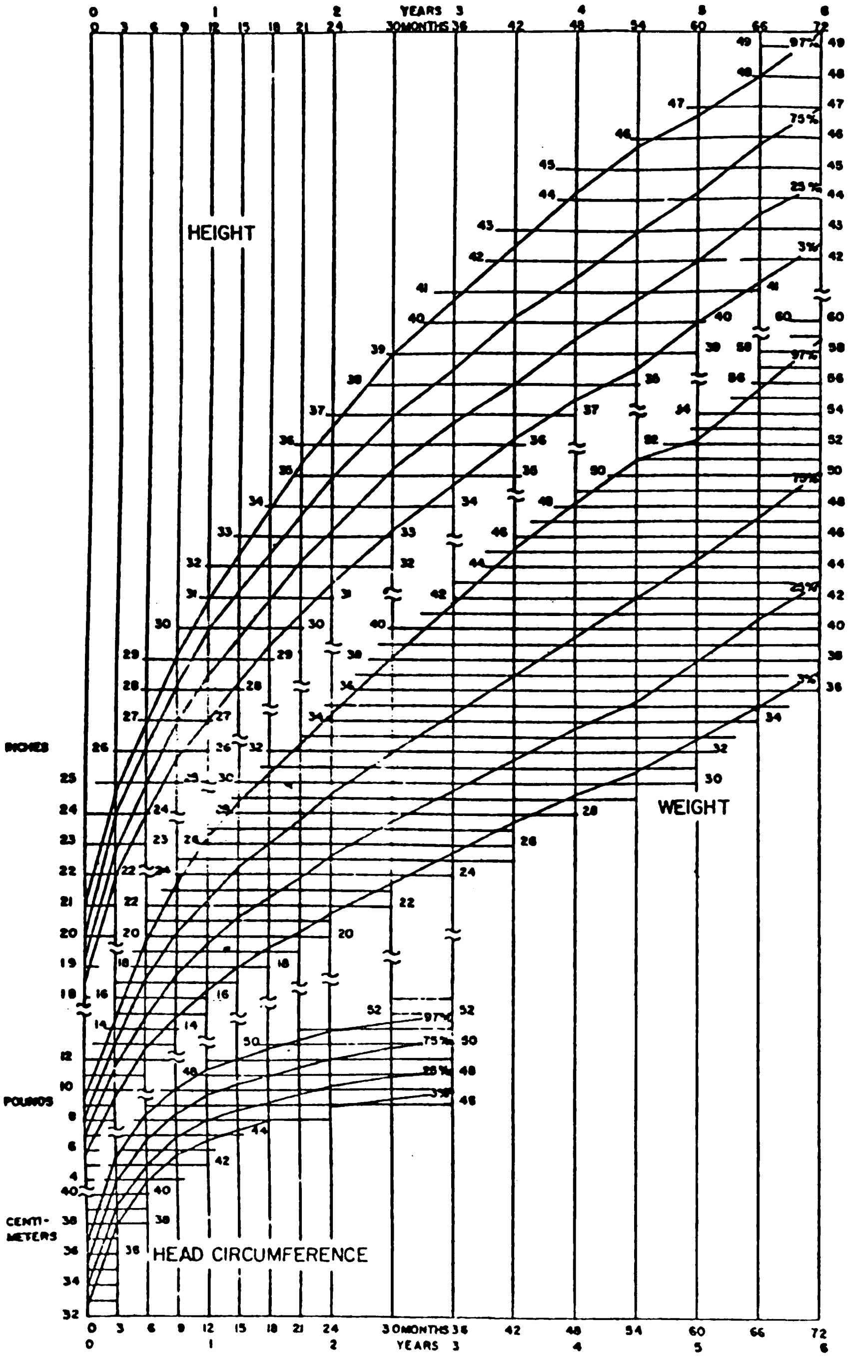


BIRTH DATE

DATE	AGE	HEIGHT	WEIGHT	HEAD

Based on data from an indigent white population by H. C. Stuart et al Watson and Lowrey, p. 60-63 Nelson, p. 56-57

GROWTH CHART
GIRLS 0-6 YEARS



BIRTH DATE

DATE	AGE	HEIGHT	WEIGHT	HEAD

Based on data from an indigent white population by H. C. Stuart et al
Watson and Lowrey, p. 60-63
Nelson, p. 56-57

3543

APPENDIX D

BAYLEY SCALES OF INFANT DEVELOPMENT

Bayley Scales of Infant Development

The Bayley Scales of Infant Development represent the most recent and reliable efforts of psychological examiners to develop an instrument to assess cognitive and motor functioning in babies aged 2 through 30 months.

Both the Mental Scale and the Motor Scale draw heavily upon three California scales: the California First-Year Mental Scale (Bayley, 1933), the California Preschool Mental Scale (Jaffa, 1934), and the California Infant Scale of Motor Development (Bayley, 1936). The content of these three scales was closely studied and many deletions, changes and additions in item content were made (Bayley, 1969).

The 1969 edition of the test consists of 163 items on the Mental Scale and 81 items on the Motor Scale. It has been standardized on a sample of 1,262 children, distributed in approximately equal numbers among fourteen age groups ranging from 2 through 30 months in selected strata of the United States population, as described in the 1960 United States Census of Population. The sample was controlled for sex and race within each age group, with further controls related to residence (urban-rural) and to education of the head of the household (Bayley, 1969).

No significant differences were found on either the Mental or Motor Scale by sex, birth order, geographical location, or parents' education. Separating the results by ethnic group (white, Negro, and Puerto Rican), the only significant difference was a consistant tendency for Negro children to obtain slightly superior scores on the Motor Scale at all ages from 3 through 14 months (Bayley, 1969).

The Bayley Scales of Infant Development are designed to provide a basis for the evaluation of a child's developmental status in the first two and one-half years of life. The Mental Scale is designed to assess sensory-perceptual acuities, and the abilities to discriminate stimuli and respond appropriately. It also attempts to assess the development of "object constancy," memory, learning and problem-solving ability in the infant and toddler. Some items assess vocalization and the beginnings of verbal communication while still other items deal with the child's ability to generalize and categorize.

The purpose of the Motor Scale is to provide a measure of the degree of control a child has over his body. Coordination of the large muscles and the finer manipulatory skills of the hands and the fingers are assessed.

Motor abilities are important in the development of the child's orientation toward his family and environment. They influence the quality of his interactions. As the infant gains mobility he becomes open to new and more varied experiences. He becomes able to make active choices and express himself in new and varied ways.

The Mental and Motor Scales correlate well with each other, usually of the order of .50 to .60, even during the first 12 months of life.

Split-half reliability coefficients for the Mental Scale range from .81 to .93, with a median value of .88. Since the Motor Scale has about half as many items as the Mental Scale, reliability coefficients for the Motor Scale tend to be somewhat lower, ranging from .68 to .92, with a median value of .84 (Bayley, 1969).

Using another statistic, that of standard error of measurement, the Mental Scale ranges from 4.2 to 6.9 standard score points, while the Motor Scale ranges from 4.6 to 9.0 (Bayley, 1969). This serves to emphasize that a test score is not a precise point on a scale, but rather an estimate of a "true" score.

When the Mental Scale score (MDI) is compared with the Motor Scale score (PDI), a difference of more than 17 to 20 points is considered to be significant at the .05 level (Bayley, 1969).

It should be emphasized that the Bayley Scales are not predictive for future intelligence as measured by such classic instruments as the Stanford-Binet. Rather, the scales provide information regarding the infant's developing facilities; his awareness of his environment and his ability to respond to and interact with it.

Marked discrepencies from the norm emphasize several potential problems however, and provide clues as to areas where remedial efforts might well be applied.

On both the MDI and the PDI a score of 100 is considered average. The more broadly defined "average" range is considered to be from about 87 to 113. Infants scoring above 113 are considered to be accelerated. Those with scores between 70 and 87 are considered borderline and suggest cause for concern and further assessment and follow-up. Children scoring below 70 and children with wide discrepancies between MDI and PDI scores (20 points or more) should be considered at risk developmentally. These children warrant close follow-up and whenever possible special programs should be planned for them to help stimulate them and enrich their environmental experiences. Neurological impairment is often evident in such children.

Premature children represent exceptions to the above rules. It is not uncommon for these children to perform more in accordance with their gestational ages than with their chronological ages. However, a "catch-up" phenomenon is usually observed and can be expected to be completed by 15 to 18 months of age.

APPENDIX E

DENVER DEVELOPMENTAL SCREENING TEST

The Denver Developmental Screening Test

The Denver Developmental Screening Test (DDST) is a short, easily administered measure of physical, motor, perceptual and cognitive development in pre-school aged children (Frankenburg and Dodds, 1967). It was devised to provide a simpler method of screening for evidence of delayed development in infants, toddlers and pre-schoolers.

The test, made up of 105 items, covers four functions: gross motor, language, fine motor--adaptive, and personal--social. It has been standardized on 1,036 presumably normal children (2 weeks to 6 years of age) whose families fitted the occupational and ethnic characteristics of the population of Denver, Colorado (Frankenburg and Dodds, 1967).

One general finding has been that, after two years of age, children of "white collar" workers tended to do better on verbal items than did children of "blue collar" workers.

Three studies have been conducted by Frankenburg and his associates (Frankenburg, Camp, Van Natta, 1971; Frankenburg & Dodds, 1967; Frankenburg, Goldstein, & Camp, 1971) in an attempt to assess the validity and reliability of the DDST. On the basis of the first two studies, the interpretation of the test scores was revised. The third study was then undertaken to cross-validate the revised method of interpretation. Non-professional health screening aides tested 2,000 children; the results of 237 were validated by testing with the Revised Bayley Infant Scale or the Stanford-Binet Intelligence Scale. Analysis of these data revealed that with the use of a revised method of interpretation, over-referrals were decreased from 21 percent to 11 percent and

underreferrals increased slightly from two to three percent. A total of 186 children varying in age between 1.5 and 76 months were tested with the DDST on two occasions 7 days apart; use of the revised method of interpretation yielded 97 percent agreement. The health aides were then retrained in the administration and interpretation of the DDST; cross validation of the revised method of interpretation with another sample of 246 children indicated only 3.2 percent overreferrals and 0.4 percent underreferrals (Frankenburg, Goldstein, & Camp, 1971).

In interpreting the results of the Denver, a test result is considered to be "abnormal" if two sectors (of the four: personal--social, fine motor--adaptive, language, and gross motor) each have two or more item delays or if one sector has two or more delays and one other sector has one delay and in the same sector the age line does not go through an item that is passed.

A test result is considered to be "questionable" if there are two or more delays in one sector or if one or more sectors have one delay and in the same sector the age line does not go through an item which is passed.

The test is interpreted as being "normal" if the performance is not "questionable" or "abnormal," (Frankenburg, Dodds, & Fandal, 1970).

Scores on the DDST correlate approximately with scores on both the Bayley and the Stanford-Binet, especially for children achieving "normal" or "abnormal" scores. Children falling in the "questionable" range however, should be rescreened since Frankenburg, et al., 1971, found that up to two-thirds of these children had DQ or IQ scores above 80.

Since the Denver Developmental Screening Test was developed as a shorthand screening instrument to be used primarily by medical professionals, it seems advisable to use it in a study where children with heart defects are being assessed. Such professionals may want to compare their findings with heart patients with the results of this study.

APPENDIX F

STANFORD-BINET INTELLIGENCE SCALE

The Stanford-Binet Intelligence Scale

The Stanford-Binet Intelligence Scale is a thoroughly standardized and reliable test of intellectual achievement. It has been known and widely used for several decades, having been most recently revised in the 1950's, resulting in the 1950 form of the scale (Terman and Merrill, 1960).

The rationale underlying the Stanford-Binet and other IQ tests is that they consist of specific samples of highly structured problem-solving behavior. The assumption is that these samples are so similar to problem-solving tasks in other structured situations that one can directly extrapolate to and predict the behavior of the child in these situations; those where he is faced with structured problem-solving tasks.

The 1960 revision retains the main characteristics of the scales from the previous tests. It is an age scale making use of age standards of performance. It attempts to measure intelligence regarded as general mental adaptability. The 1960 scale incorporates into a single form the best subtests of the 1937 scales. The selection of the actual subtests was based on records of tests administered over a five-year period (1950-1954) to 4498 subjects ranging in age from 2½ to 18 years.

In scoring the Stanford-Binet, the child's "mental age" (MA) is compared with his chronological age (CA) to result in his intelligence quotient or IQ. An IQ of 100 is considered average. The overall average range extends from 90 to 109. The "low average" range extends from 80 to 89. Children scoring between 70 and 79 are classified as "borderline" defective." Scores below 70 are considered to be

representative of mental defectiveness or retardation. Roughly 3 percent of the general population falls in this category (Terman & Merrill, 1960).

APPENDIX G

NEONATAL PERCEPTION INVENTORY

The Neonatal Perception Inventory

The Neonatal Perception Inventory (NPI) was devised by Broussard and Hartner for their work with mothers of newborn infants. They were concerned with trying to predict how a primiparous mother might respond to her baby based on the extent to which her baby was perceived by her to be similar to or different from her conception of the average.

In their research, 120 full-term, normal, first born infants were categorized at one month of age into a high-risk or low-risk group for possible development of emotional and developmental deviations. The predictions were based on measurements of the mother's perception of her infant as compared to the average. At age 4½ the children were evaluated by two child psychiatrists who had no knowledge of the children's predictive risk rating. A statistically significant association was evident between prediction and outcome, (Broussard & Hartner, 1970).

The inventories that were used asked the mothers to rate, first the average baby and then their baby, on such variables as crying, feeding problems, spitting up or vomiting, sleeping difficulties, bowel movement problems, and predictability of eating and sleeping patterns.

A "Degree of Bother Inventory" was also developed by Broussard and Hartner (1971). This form asks mothers to describe how much they were bothered by their baby's behaviors in regard to the same, above mentioned variables.

While Broussard and Hartner used their instrument only with primiparous mothers and only during the neonatal period, the plan in this study is to ask mothers of cardiac children to retrospectively rate both their child's behaviors and how bothered they were by them, regardless of the child's present age.

Our purpose is to attempt to see if a mother's responses vary depending upon the nature and severity of her child's defect. The forms used (essentially the same as those used by Broussard and Hartner) are on the following three pages.

Average Baby and Your Baby Scales--Method of Scoring

The Average Baby form elicits the mother's concept of the average baby's behavior. The Your Baby form elicits her rating of her own child. Each of these instruments consists of six single item scales. Values of 1-5 are assigned to each of these scales for each of the inventories. The blank signified "none" is valued as 1 and "a great deal" has a value of 5. The lower values on the scale represent the more desirable behavior.

The six scales are totaled with no attempt at weighting the scales for each of the inventories separately. Thus, a total score is obtained for the Average Baby and a total score is obtained for the Your Baby.

The total score of the Your Baby form is then subtracted from the Average Baby form. The discrepancy constitutes the Neonatal Perception Inventory score. (Broussard & Hartner, 1971).

Degree of Bother Inventory--Method of Scoring

The Degree of Bother Inventory to assess problems of infant behavior is administered following the other NPI items. The total problem score is calculated by assigning values of 1-4 to each of the six items on the inventory. These are totaled with no attempt in weighting the items. Broussard and Hartner (1971) found the Degree of Bother Inventory to have high face validity.

Neonatal Perception Inventory

AVERAGE BABY

You probably have some ideas of what most little babies are like. Please check the blank you think best describes the AVERAGE BABY.

How much crying do you think the average baby does?

a great deal	a good bit	moderate amount	very little	none

How much trouble do you think the average baby has in feeding?

a great deal	a good bit	moderate amount	very little	none

How much spitting up or vomiting do you think the average baby does?

a great deal	a good bit	moderate amount	very little	none

How much difficulty do you think the average baby has in sleeping?

a great deal	a good bit	moderate amount	very little	none

How much difficulty does the average baby have with bowel movements?

a great deal	a good bit	moderate amount	very little	none

How much trouble do you think the average baby has in settling down to a predictable pattern of eating and sleeping?

a great deal	a good bit	moderate amount	very little	none

Neonatal Perception Inventory

YOUR BABY

Please check the blank you think best describes your child's behavior during the first six months of his or her life.

How much crying did your baby do?

a great deal	a good bit	moderate amount	very little	none

How much trouble did your baby have with feeding?

a great deal	a good bit	moderate amount	very little	none

How much spitting up or vomiting did your baby do?

a great deal	a good bit	moderate amount	very little	none

How much difficulty did your baby have in sleeping?

a great deal	a good bit	moderate amount	very little	none

How much difficulty did your baby have with bowel movements?

a great deal	a good bit	moderate amount	very little	none

How much trouble did your baby have in settling down into a predictable pattern of eating and sleeping?

a great deal	a good bit	moderate amount	very little	none

Neonatal Perception Inventory

DEGREE OF BOTHER INVENTORY

Listed below are some of the things that have sometimes bothered other mothers in caring for their babies. We would like to know if you were bothered about any of these. Please place a check in the blank that best describes how much you were bothered by your baby's behavior in regard to these.

Crying	a great deal	somewhat	very little	none
Spitting up or vomiting	a great deal	somewhat	very little	none
Sleeping	a great deal	somewhat	very little	none
Feeding	a great deal	somewhat	very little	none
Elimination	a great deal	somewhat	very little	none
Lack of a predict-table schedule	a great deal	somewhat	very little	none
Other: (Specify)				
_____	a great deal	somewhat	very little	none
_____	a great deal	somewhat	very little	none
_____	a great deal	somewhat	very little	none
_____	a great deal	somewhat	very little	none

APPENDIX H

CARDIAC SYMPTOM GROUPS--INDIVIDUAL SUBJECT DATA

Table 10

Individual Subject Data Values--Family Information Variables

Group	Case #	Age	Sex	Age of mother at birth	Age of father at birth	Mother educ.	Father educ.	Father occ.*	Mother emp.
I	18	01:07	F					3	-
	26	05:10	F	20	24	11	12	4	-
	27	00:10	F	19	24	12	12	2	-
	46	03:06	F	31	31	16	18	5	+
	47	05:08	M	33	36	10	08	2	-
	49	03:07	M	25	25	12	12	3	+
	56	05:02	F	19		11			-
	63	02:00	F	28	30	17	20	5	+
	76	02:01	M	29	30	13	16	5	+
	13	00:07	F	34	41	10	12	3	-
	53	00:10	M	26	28	12	12	3	-
	74	03:07	M	19	20	11	12	2	-
	67	00:05	F	23	26	12	13	3	-
	32	05:02	F	21	24	09	12	1	-
	Mean	02:11	M=5 F=9	25.15	28.52	12.00	13.25	3.15	+4 -10
II	43	10:01	M	29	29	15	20	5	-
	05	05:10	F	23	23	15	18	4	+
	06	05:07	M	24	31	11	12	3	-
	15	00:07	F	23	24	14	13	2	-
	12	02:03	M	28	28	12	12	3	-
	16	00:07	F	26	28	12	16	1	+
	21	03:02	M	25	26	12			-
	22	02:01	F	25	26	16	16	5	-
	28	05:01	F	19	22	12	12	3	-
	33	04:09	F	21	22	12	12	1	-
	44	04:08	F	16	18	10	12	3	-
	57	03:09	F	35		15			+
	59	02:04	F	18	18	12	12	3	-
	65	04:00	M	21	34	11	08	2	-
	69	03:07	F	29	31	13	14	4	-
	58	03:01	M	23	34	10	11	2	-
	75	04:05	M	31	38	12	16	5	-
	Mean	03:11	M=7 F=10	24.47	27.00	12.59	13.60	3.07	+3 -14

* Father occupation variable values: 1 = unemployed; 2 = unskilled; 3 = semi-skilled; 4 = skilled; 5 = professional.

Table 10 (continued):

Group	Case #	Age	Sex	Age of mother at birth	Age of father at birth	Mother educ.	Father educ.	Father occ.	Mother emp.
III	20	08:97	F	23	29	14	16	5	-
	25	00:09	M	25	27	12	12	3	-
	38	11:03	M	20	24	09	10	2	+
	39	07:10	M	23	25	12	10	1	-
	48	06:06	M	20	20	12	14	5	+
	50	08:08	M	34	37	11	12	3	-
	52	04:04	M	24	28	12	12	3	-
	61	02:02	F	23	31	13	13	3	-
	66	08:08	F	22	33	12	16	1	+
	72	02:00	M	20	33	12	12	4	-
	73	02:03	M	22	24	12	12	3	-
	19	01:06	F	20	20	12	12	2	-
	70	01:08	M	20	27	10	06	2	-
	Mean	05:01	M=9 F=4	22.77	27.54	11.69	12.00	2.85	+3 -10
IV	02	03:06	M	27	29	16	15	5	-
	04	05:08	M	23	24	13	16	3	+
	10	06:10	M	19	20	12	13	3	-
	14	02:05	M	29	33	16	25	5	+
	23	04:10	M	28	29	12	12	3	+
	29	04:08	M	26	30	12	16	4	-
	30	04:08	M	26	30	12	16	4	-
	31	03:07	M	24	26	13	16	5	-
	35	06:08	F	25	25	12	14	3	+
	36	02:07	M	25	29	14	16	5	-
	37	05:04	F	26	28	12	14	1	-
	40	05:10	M	21	20	12	12	2	-
	54	00:11	F	26	27	13	13	4	-
	68	03:00	M	23	23	12	12	3	-
	Mean	04:04	M=11 F=3	24.86	26.64	12.93	15.00	3.57	+4 -10

Table 11

Individual Subject Data Values--Neonatal Information Variables*

Group	Case #	PP	Labor	AN	Birth wgt.	Birth lgth.	Gest. age	ICU SCN	TRP	Days in hosp.	Br. fed
I	18				4:07	19.5	35	+	+	55	-
	26	+	2	-	7:04	19.5	40	-	-	04	+
	27	-	2	+	7:02	21.0	40	-	-	03	-
	46	+	3	+	7:14	20.5	40	-	-	05	-
	47	+	1	-	6:12	20.5	37	-	+	24	-
	49	-	1	+	4:06	18.5	34	+	-	18	-
	56	-			7:00	20.5	40	-	-	05	-
	63	+	2	-	8:02	20.0	40	-	-	02	+
	76	+	6	-	7:13	21.0	40	-	-	05	-
	13	-	9	-	6:04	20.0	40	-	-	14	-
	53	-	2	-	8:05	20.0	38	-	-	08	-
	74	-	9	-	7:05	21.0	42	-	-	04	-
	67	+	1	+	8:10	21.7	40	-	-	06	+
	32	+	2	+	7:10	21.0	41	-	-	04	-
	Mean	+8 -6	3.33	+7 -7	7:00	20.34	39.07	+2 -12	+2 -12	08.36	+3 -11
II	43	-	2	+	7:08	19.0	40	-	-	05	+
	05	+	8	+	6:00	19.5	40	-	-	04	-
	06	+	1	-	8:00	21.0	40	-	-	04	-
	15	+	4	-	9:01	20.5	39	-	-	08	+
	12	+	2	+	5:11	20.0	41	-	-	05	-
	16	-	8	+	8:12	22.2	40	-	-	08	+
	21	+	6	+	9:06	21.0	40	+	+	30	-
	22	+	3	+	7:07	20.0	40	-	-	04	+
	28	-	3	-	7:13	20.0	40	-	-	05	-
	33	-	6	-	8:02	20.5	40	+	-	09	+
	44	+	7	+	6:11	19.5	40	-	-	03	-
	57				6:15	19.5	40	-	-	08	-
	59	-	1	+	7:08	22.0	40	-	-	05	-
	65	+	3	+	7:01	20.0	40	-	-	03	-
	69	-	2	-	8:12	21.0	40	+	-	07	-
	58	-	5	+	6:03	19.0	40	-	-	03	-
	75	-			7:06	17.0	40	-	-	05	-
	Mean	+9 -8	4.07	+12 -5	7:09	20.04	40.00	+3 -14	+1 -16	6.82	+5 -12

* Definitions of variable symbols and abbreviations: "PP" - planned pregnancy; "Labor" - hours of labor: 1 = 1-2 hours, 2 = 3-4 hours, 3 = 5-6 hours, 4 = 7-8 hours, 5 = 9-10 hours, 6 = 11-12 hours, 7 = 13-14 hours, 8 = 15-16 hours, 9 = more than 16 hours; "AN" - anesthetic administered; "Birth wgt." - birth weight in pounds and ounces; "Birth lgth.: - birth length in inches; "Gest. age" - gestational age in weeks; "ICU - SCN" - admission to neonatal intensive care unit or special care nursery: "TRP" - transported to another hospital; "Br. fed" - breast-fed.

Table 11 (continued):

Group	Case #	PP	Labor	AN	Birth wgt.	Birth lgth.	Gest. age	ICU SCN	TRP	Days in hosp.	Br. fed
III	20	+	3	+	7:06	19.0	40	-	-	04	-
	25	-	2	-	7:07	20.5	40	+	+	05	-
	38	-	3	-	7:14	21.0	40	-	-	03	-
	39	-	1	-	6:07	19.0	41	-	-	06	+
	48	+	3	-	8:07	20.0	40	-	-	04	+
	50	-	1	+	9:05	20.0	40	-	-	04	+
	52	+	1	-	7:11	21.0	40	-	-	04	-
	61	+	2	-	7:12	19.0	40	-	-	05	-
	66	+	4	+	7:05	20.0	40	-	-	05	-
	72	+	1	-	8:01	20.0	40	+	+	21	+
	73	+	2	-	7:02	19.0	40	-	+	08	-
	19	+	2	-	7:00	21.5	40	-	-	04	-
	70	-	4	+	7:09	19.5	40	-	-	08	+
	Mean	+8 -5	2.23	+4 -9	7:10	19.98	40.08	+2 -11	+3 -10	6.23	+5 -8
IV	02	+	6	+	8:05	21.0	40	-	-	05	+
	04	+	3	-	7:06	21.5	39	-	-	04	-
	10	+	2	-	6:14	19.5	40	-	-	05	-
	14	+	1	+	6:06	18.0	40	-	-	04	-
	23	+	2	-	5:02	18.0	36	+	-	07	-
	29	+	1	+	6:04	19.0	40	-	-	10	+
	30	+	1	+	7:03	20.0	40	-	-	10	+
	31	+	2	-	5:12	18.5	37	-	-	05	+
	35	+	6	-	6:00	19.0	39	-	-	03	-
	36	+	1	-	9:02	19.5	40	-	-	04	-
	37	-	2	+	6:07	21.5	40	-	-	05	-
	40	-	1	+	7:08	18.5	38	-	-	05	-
	54	+	1	+	6:15	18.0	40	-	-	04	+
	68	+	2	+	8:14	22.0	40	-	-	04	-
	Mean	+12 -2	2.21	+8 -6	7:00	19.57	39.21	+1 -13	+0 -14	5.79	+5 -9

Table 12

Individual Subject Data Values--Catheterization and Surgery Variables*

Group	Case #	Cth.	Cth. bgh	Cth. bly	Cth. #	Srg.	Srg. bly	Srg. #	Fut. Cth.	Fut. Srg.
I	18	+	+	+	1	+	+	1	+	+
	26	+	-	+	3	+	-	1	-	-
	27	+	-	+	1	-	-	0	+	+
	46	+	-	+	1	-	-	0	+	+
	47	+	+	+	4	-	-	0	+	+
	49	+	-	+	1	-	-	0	+	+
	56	+	-	-	2	+	-	1	+	+
	63	+	-	+	1	-	-	0	+	+
	76	+	-	+	1	+	+	1	-	-
	13	+	-	+	1	-	-	0	+	+
	53	+	-	+	2	+	+	1	+	+
	74	+	-	+	1	+	-	1	+	+
	67	+	-	+	1	+	+	1	+	+
	32	+	-	-	1	+	-	1	-	-
	Mean	+14 -0	+2 -12	+12 -2	1.50	+8 -6	+4 -10	0.57	+11 -3	+11 -3
II	43	+	-	+	2	+	-	1	-	-
	05	-	-	-	0	-	-	0	-	-
	06	-	-	-	0	-	-	0	-	-
	15	-	-	-	0	-	-	0	+	+
	12	-	-	-	0	-	-	0	+	+
	16	-	-	-	0	-	-	0	-	-
	21	+	-	-	1	+	-	1	-	-
	22	+	-	+	1	+	+	1	+	-
	28	+	-	-	1	+	-	1	-	-
	33	-	-	-	0	-	-	0	-	-
	44	+	-	-	1	+	-	1	+	-
	57	+	-	+	2	+	+	1	+	+
	59	+	-	+	1	-	-	0	+	+
	65	+	-	-	1	+	-	1	-	-
	69	+	-	-	1	+	-	1	-	-
	58	+	-	-	1	+	-	1	-	-
	75	+	-	-	2	+	-	1	-	-
	Mean	+11 -6	+0 -17	+3 -14	0.82	+10 -7	+2 -15	0.59	+6 -11	+4 -13

* Definitions of variable symbols and abbreviations: "Cth." - catheterization to date; "Cth. bgh" - catheterization before going home from hospital as a newborn; "Cth. bly" - catheterization before one year of age; "Cth. #" - total number of catheterizations to date; "Srg." - surgery to date; "Srg. bly" - surgery before one year of age; "Srg. #" - total number of surgeries to date; "Fut. Cth." - future catheterization planned; "Fut. Srg." - future surgery planned.

Table 12 (continued):

Group	Case #	Cth.	Cth. bgh	Cth. bly	Cth. #	Srg.	Srg. bly	Srg. #	Fut. Cth.	Fut. Srg.
III	20	+	-	-	2	+	-	2	-	-
	25	+	+	+	1	-	-	0	+	+
	38	+	-	-	4	+	-	2	+	+
	39	+	-	+	3	+	+	2	-	-
	48	+	-	-	3	+	-	1	-	-
	50	+	-	+	4	+	+	2	+	-
	52	+	-	-	1	+	-	1	+	-
	61	+	-	+	1	-	-	0	+	+
	66	+	-	-	1	+	-	1	+	-
	72	+	+	+	2	+	+	2	+	-
	73	+	+	+	2	+	+	2	+	+
	19	+	-	+	1	-	-	0	+	+
	70	+	-	+	1	+	+	1	+	+
	Mean	+13	+3	+8	2.00	+10	+5	1.23	+10	+6
		-0	-10	-5		-3	-8		-3	-7
IV	02	-	-	-	0	-	-	0	-	-
	04	-	-	-	0	-	-	0	-	-
	10	-	-	-	0	-	-	0	-	-
	14	-	-	-	0	-	-	0	-	-
	23	-	-	-	0	-	-	0	-	-
	29	-	-	-	0	-	-	0	-	-
	30	-	-	-	0	-	-	0	-	-
	31	-	-	-	0	-	-	0	-	-
	35	-	-	-	0	-	-	0	-	-
	36	-	-	-	0	-	-	0	-	-
	37	-	-	-	0	-	-	0	-	-
	40	-	-	-	0	-	-	0	-	-
	54	-	-	-	0	-	-	0	-	-
	68	+	-	+	1	-	-	0	+	-
	Mean	+1	+0	+1	0.07	+0	+0	0.00	+1	+0
		-13	-14	-13		-14	-14		-13	-14

Table 13

Individual Subject Data Values--Physical Measurement Information Variables*

Group	Case #	Weight	Weight %	Height	Height %	Head Circ.	Head Circ. %
I	18	14.5	03	29.7	05	46.5	25
	26	41.2	03	43.0	15	50.5	20
	27	11.5	03	26.0	03	42.0	03
	46	33.0	45	40.5	80	50.0	65
	47	34.0	03	41.5	03	54.5	90
	49	28.0	03	34.0	03	50.5	30
	56	40.0	40	45.5	50	50.0	40
	63	26.0	30	33.0	25	46.5	10
	76	25.0	22	34.7	45	50.7	85
	13	09.0	03	25.5	25	39.5	03
	53	16.5	10	29.5	75	45.0	20
	74	34.0	35	38.5	20	49.0	25
	67	12.5	10	26.0	80	41.5	25
	32	37.0	20	43.5	50	50.7	50
	Mean		16.43		34.21		35.07
II	43	58.5	05	54.0	30	53.2	55
	05	42.0	20	45.2	40	51.0	50
	06	44.0	35	44.0	31	51.5	35
	15	17.2	80	26.0	75	45.7	95
	12	28.0	30	32.2	03	46.0	03
	16	16.7	75	28.0	97	43.0	50
	21	32.0	30	36.0	03	49.5	22
	22	28.0	55	35.0	65	49.5	80
	28	44.0	35	44.5	35	54.4	95
	33	36.0	20	41.0	20	51.5	70
	44	34.0	10	40.0	05	52.0	60
	57	29.0	05	36.2	03	48.5	20
	59	29.0	50	35.5	50	48.0	30
	65	38.0	60	39.5	20	52.0	75
	69	35.0	55	40.5	80	51.0	75
	58	37.0	82	37.0	20	49.0	18
	75	38.0	50	43.2	75	52.0	50
	Mean		41.00		38.35		51.94

* Definitions of variable symbols and abbreviations: "Weight" - measured in pounds; "Weight %" - percentile weight for age; "Height" - measured in inches; "Height%" - percentile height for age; "Head Circ." - head circumference in centimeters; "Head Circ.%" - percentile head circumference for age.

Table 13 (continued):

Group	Case #	Weight	Weight %	Height	Height %	Head Circ.	Head Circ. %
III	20	44.0	03	46.7	03	49.5	03
	25	12.5	03	26.0	03	42.0	03
	38	84.0	50	59.5	50	53.5	50
	39	54.0	55	50.0	75	50.5	10
	48	50.0	50	49.5	80	52.0	40
	50	50.0	45	50.5	60	53.2	75
	52	32.0	10	39.5	10	50.0	20
	61	30.0	75	34.5	40	49.5	75
	66	57.0	55	51.0	60	50.5	10
	72	28.2	60	34.0	30	49.0	50
	73	19.7	03	34.0	15	47.9	10
	19	24.0	20	32.0	20	47.0	10
	Mean		38.77		38.92		29.31
IV	02	36.0	70	40.5	80	51.0	70
	04	40.0	15	44.0	23	51.5	26
	10	49.0	50	47.0	70	53.5	50
	14	30.0	50	37.0	77	50.7	75
	23	42.0	58	43.0	38	52.5	60
	29	35.0	32	39.0	01	51.5	35
	30	42.0	70	43.5	60	53.0	75
	31	42.0	97	41.7	90	51.5	80
	35	47.0	50	46.7	60	52.5	75
	36	30.0	46	36.5	54	49.5	35
	37	46.0	70	44.7	60	51.5	80
	40	44.0	25	44.0	20	52.0	25
	54	22.0	76	28.0	25	47.0	80
	68	31.0	40	39.7	85	50.5	65
	Mean		53.50		53.07		59.36

Table 14

Individual Subject Data Values--Psychological Assessment Variables*

Group	Case #	NPI OWN	NPI AVG	NPI DOB	DDST	BSID MDI	BSID PDI	SBIQ
I	18				A-1	070	056	
	23	13	16	10	N-3			091
	27	19	16	14	Q-2	108	073	
	46	20	13	18	N-3			111
	47	17	15	15	Q-2			072
	49	11	14	11	A-1			061
	56				N-3			100
	63	07	13	06	Q-2	079	096	
	76	08	12	06	N-3	109	103	
	13	20	17	15	N-3	088	076	
	53	19	14	08	Q-2	108	078	
	74	13	14	11	Q-2			085
	67	18	14	14	N-3	096	099	
	32	23	18	22	N-3			100
	Mean	15.67	14.67	12.50	2.36	94.00	83.00	88.57
II	43	17	13	13				094
	05	16	14	14	N-3			103
	06	11	11	10	A-1			088
	15	09	12	08	N-3	115	132	
	12	16	14	17	N-3	065	070	
	16	12	14	13	N-3	123	117	
	21	11	13	13	A-1			073
	22	17	11	16	N-3	121	109	
	28	24	14	19	N-3			107
	33	19	15	18	Q-2			094
	44	19	17	12	Q-2			088
	57				Q-2			092
	59	12	13	09	N-3	077	099	
	65	22	20	06	N-3			105
	69	19	17	13	A-1			066
	58	11	13	05	N-3			077
	75	22	14	20	N-3			105
	Mean	16.06	14.31	12.88	2.44	100.20	105.40	91.00

* Definitions of variable symbols and abbreviations: "NPI-OWN" - Neonatal Perception Inventory, "Own Baby" Rating Scale; "NPI-AVG" - Neonatal Perception Inventory, "Average Baby" Rating Scale; "NPI-DOB" - Neonatal Perception Inventory, "Degree of Bother" Rating Scale (in the above three scales lower numbers indicate more favorable ratings); "DDST" - Denver Developmental Screening Test (for computation purposes, normal = 3, questionable = 2, abnormal = 1); "BSIDMDI" - Bayley Scales of Infant Development--Mental Scale; "BSIDPDI" - Bayley Scales of Infant Development--Motor Scale; "SBIQ" - Stanford-Binet Intelligence Quotient (in the above three scales, 100 = average score for age.

Table 14 (continued):

Group	Case #	NPI OWN	NPI AVG	NPI DOB	DDST	BSID MDI	BSID PDI	SBIQ
III	20	15	13	09				093
	25	10	14	09	Q-2	089	058	
	38	15	14	12				104
	39	27	14	21				089
	48	10	12	12				091
	50	10	12	06				093
	52	22	17	19	Q-2			091
	61	17	14	15	Q-2	108	108	
	66	12	17	10				093
	72	25	15	14	N-3	096	077	
	73	15	12	14	Q-2	087	075	
	19	15	12	14	N-3	109	094	
	70	20	17	14	N-3	110	102	
	Mean	16.62	14.31	13.00	2.43	99.83	85.67	93.86
IV	02	13	16	13	N-3			109
	04	12	13	11	N-3			103
	10	16	18	13				120
	14	12	14	12	Q-2	084	088	
	23	14	14	15	N-3			103
	29	14	13	14	N-3			088
	30	11	13	09	N-3			096
	31	18	16	13	N			107
	35	14	17	11				089
	36	14	15	07	N-3	124	102	
	37	13	15	12	Q-2			083
	40	13	20	10	N-3			084
	54	10	13	08	N-3	117	098	
	68	08	11	08	N-3			089
	Mean	13.00	14.86	11.14	2.83	108.33	98.00	97.36

APPENDIX I

GROWTH PERCENTILE GROUPS--

PSYCHOLOGICAL ASSESSMENT VARIABLES

Table 15

Weight Percentile Groups--Psychological Assessment Variables

All subjects were assigned to groups based on their weight percentile values as follows: "W-I"--all subjects above the 16th percentile for weight; "W-II"--all subjects at or below the 16th percentile and above the 3rd percentile for weight; "W-III"--all subjects at or below the 3rd percentile for weight. (Variable symbols and abbreviations are the same as in previous tables.)

GRP	W-I		W-II		W-III		Totals		
	N	X	N	X	N	X	N	X	F	df
VAR		S.D.		S.D.		S.D.		S.D.	ratio	
NPI	41	15.02	6	17.83	8	3.59	55	15.13	0.97	2/52
OWN		4.98		3.31		3.59		4.59		
NPI	41	14.39	6	15.33	8	1.69	55	14.53	0.53	2/52
AVG		2.22		1.86		1.69		2.09		
NPI	41	12.37	6	12.83	8	2.64	55	12.38	0.05	2/52
DOB		4.31		3.65		2.64		3.99		
DDST	35	2.66	6	2.33	8	0.76	53	2.51	3.62*	2/46
		0.64		0.52		0.76		0.63		
BSID	14	102.64	2	102.00	5	88.40	21	99.19	1.24	2/18
MDI		19.13		8.49		13.46		16.66		
BSID	14	100.07	2	88.50	5	67.60	21	91.33	9.32@	2/18
PDI		15.60		14.85		9.76		13.73		
SBIQ	28	94.71	5	94.20	4	79.25	37	92.97	2.93+	2/34
		12.27		5.50		15.41		11.67		

\+ indicates significance at .10 level.
* indicates significance at .05 level.
@ indicates significance at .01 level.

Table 16

Height Percentile Groups--Psychological Assessment Variables

All subjects were assigned to groups based on their height percentile values as follows: "H-I"--all subjects above the 16th percentile for height; "H-II"--all subjects at or below the 16th percentile and above the 3rd percentile for height; "H-III"--all subjects at or below the 3rd percentile for height. (Variable symbols and abbreviations are the same as in previous tables.)

GRP	W-I		W-II		W-III		Totals		
	N	$\bar{X}$	N	$\bar{X}$	N	$\bar{X}$	N	$\bar{X}$	F	df
VAR		S.D.		S.D.		S.D.		S.D.	ratio	
NPI	43	15.37	4	17.25	8	14.13	55	15.33	0.60	2/52
OWN		4.95		4.03		3.23		4.62		
NPI	43	14.53	4	15.50	8	14.00	55	14.53	0.67	2/52
AVG		2.23		2.38		1.07		2.08		
NPI	43	12.19	4	13.75	8	12.75	55	12.38	0.31	2/52
DOB		4.22		3.86		2.87		3.97		
DDST	36	2.69	5	2.00	8	2.00	49	2.51	6.01@	2/46
		0.58		0.71		0.76		0.61		
BSID	16	104.00	2	78.50	3	87.33	21	99.19	3.18+	2/18
MDI		15.48		12.02		21.55		15.28		
BSID	16	99.00	2	65.50	3	67.00	21	91.24	10.08@	2/18
PDI		14.85		14.35		7.94		13.45		
SBIQ	28	96.00	3	91.00	6	79.83	37	92.97	4.99*	2/34
		11.51		3.00		13.04		11.11		

\+ indicates significance at .10 level.
* indicates significance at .05 level.
@ indicates significance at .01 level.

Table 17

Head Circumference Percentile Groups--Psychological Assessment Variables

All subjects were assigned to groups based on their head circumference percentile values as follows: "HC-I"--all subjects above the 16th percentile for head circumference; "HC-II"--all subjects at or below the 16th percentile and above the 3rd percentile for head circumference; "HC-III"--all subjects at or below the 3rd percentile for head circumference. (Variable symbols and abbreviations are the same as in previous tables).

GRP	HC-I		HC-II		HC-III		Totals		
VAR	N	$\bar{X}$ S.D.	N	$\bar{X}$ S.D.	N	$\bar{X}$ S.D.	N	$\bar{X}$ S.D.	F ratio	df
NPI OWN	45	15.16 4.46	5	16.20 7.66	5	16.00 3.94	55	15.33 4.66	0.16	2/52
NPI AVG	45	14.49 2.17	5	14.60 2.30	5	14.80 1.64	55	14.53 2.10	0.05	2/52
NPI DOB	45	12.27 3.93	5	13.00 5.57	5	12.80 3.63	55	12.38 3.99	0.10	2/52
DDST	42	2.52 0.71	3	2.33 0.58	4	2.50 0.58	49	2.51 0.68	0.11	2/46
BSID MDI	14	104.07 17.18	3	92.00 16.09	4	87.50 17.60	21	99.19 16.26	1.76	2/18
BSID PDI	14	97.57 18.78	3	91.00 14.18	4	69.25 7.89	21	91.24 16.08	4.34*	2/18
SBIQ	34	93.09 13.18	2	91.00 2.83	1	93.00 0.00	37	92.97 12.63	0.02	2/34

\+ indicates significance at .10 level.
* indicates significance at .05 level.
@ indicates significance at .01 level.

Table 18

Failure-to-thrive -vs.- non-Failure-to-thrive Groups--
Psychological Assessment Variables

All subjects were assigned to groups based on their combined weight, height, and head circumference percentile values as follows: "F-I"--all subjects above the 16th percentile for weight, height, and head circumference; "F-III"--all subjects at or below the 3rd percentile for weight, height, and head circumference.

No "F-II" group was formed because no subjects were at or below the 16th percentile and above the 3rd percentile in all three measurement categories. (Variable symbols and abbreviations are the same as in previous tables.)

GRP	F-I		F-III		Totals			
	N	$\bar{X}$ S.D.	N	$\bar{X}$ S.D.	N	$\bar{X}$ S.D.	F ratio	df
VAR								
NPI OWN	34	14.97 4.71	3	14.67 4.51	37	14.95 4.63	0.01	1/35
NPI AVG	34	14.38 2.32	3	14.33 1.53	37	14.38 2.25	0.00	1/35
NPI DOB	34	12.12 4.24	3	10.67 2.89	37	12.00 4.11	0.33	1/35
DDST	30	2.70 0.60	2	2.00 0.00	32	2.66 0.58	2.68	1/30
BSID MDI	11	107.55 15.69	2	98.50 13.44	13	106.15 14.84	0.58	1/11
BSID PDI	11	103.00 14.65	2	65.50 10.61	13	97.23 13.72	11.59@	1/11
SBIQ	24	96.21 12.27	1	93.00 0.00	25	96.08 12.01	0.07	1/23

\+ indicates significance at .10 level.
* indicates significance at .05 level.
@ indicates significance at .01 level.

Table 19

Summary Table of Growth Percentile Groups--Psychological Assessment Variables

GROUP	DDST			BSIDMDI			BSIDPDI			SBIQ		
	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.
W-I	35	2.66	0.64	14	102.64	19.13	14	100.07	15.60	28	94.71	12.27
W-II	6	2.33	0.52	2	102.00	8.49	2	88.50	14.85	5	94.20	5.50
W-III	8	2.00	0.76	5	88.40	13.46	5	67.60	9.76	4	79.25	15.41
Totals	49	2.51	0.63	21	99.19	16.66	21	91.33	13.72	37	92.97	11.67
F ratio		3.62*			1.24			9.32@			2.93+	
df		2/46			2/18			2/18			2/34	
H-I	36	2.69	0.58	16	104.00	15.48	16	99.00	14.85	28	96.00	11.51
H-II	5	2.00	0.71	2	78.50	12.02	2	65.50	14.35	3	91.00	3.00
H-III	8	2.00	0.76	3	87.33	21.55	3	67.00	7.94	6	79.83	13.04
Totals	49	2.51	0.61	21	99.19	15.28	21	91.24	13.45	37	92.97	11.11
F ratio		6.01@			3.18+			10.08@			4.99*	
df		2/46			2/18			2/18			2/34	
HC-I	42	2.52	0.71	14	104.07	17.18	14	97.57	18.78	34	93.09	13.18
HC-II	3	2.33	0.58	3	92.00	16.09	3	91.00	14.18	2	91.00	2.83
HC-III	4	2.50	0.58	4	87.50	17.60	4	69.25	7.89	1	93.00	0.00
Totals	49	2.51	0.68	21	99.19	16.25	21	91.24	16.08	37	92.97	12.63
F ratio		0.11			1.76			4.34*			0.02	
df		2/46			2/18			2/18			2/34	
F-I	30	2.70	0.06	11	107.55	15.69	11	103.00	14.65	24	96.21	12.27
F-III	2	2.00	0.00	2	98.50	13.44	2	65.50	10.61	1	93.00	0.00
Totals	32	2.66	0.58	13	106.15	14.84	13	97.23	13.72	25	96.08	12.01
F ratio		2.68			0.58			11.59@			0.07	
df		1/30			1/11			1/11			1/23	

\+ indicates significance at .10 level.
* indicates significance at .05 level.
@ indicates significance at .01 level.

APPENDIX J

CHILDREN HAVING HAD SURGERY COMPARED TO CHILDREN NOT HAVING HAD SURGERY-- PHYSICAL AND PSYCHOLOGICAL VARIABLES

Table 20

Surgery -vs.- non-Surgery Groups--Physical Measurement Variables

For the purposes of this comparison all children with only insignificant heart ailments (Group IV) were excluded since they would probably never require surgery.

The remaining subjects were assigned to the two groups as follows: "Surgery"--all children who had already undergone a surgical procedure (either a palliative procedure or a complete repair); "non-Surgery"--all children who had not yet undergone surgery.

GRP	SURGERY N=28		NON-SURGERY N=16		Totals N=44 $\bar{X}$	S.D.	F ratio	df
VAR								
Weight%	31.46	23.21	34.38	29.17	32.52	25.20	0.13	1/42
Height%	38.53	27.69	34.88	30.47	37.20	28.38	0.17	1/42
Head Circum-ference%	39.93	26.81	39.81	31.94	39.89	28.41	0.00	1/42

Table 21

Surgery -vs.- non-Surgery Groups--Psychological Assessment Variables

For the purposes of this comparison all children with only insignificant heart ailments (Group IV) were excluded since they would probably never require surgery.

The remaining subjects were assigned to the two groups as follows: "Surgery"--all children who had already undergone a surgical procedure (either a palliative procedure or a complete repair); "non-Surgery"--all children who had not yet undergone surgery. (Variable symbols and abreviations are the same as in previous tables).

GRP	SURGERY			NON-SURGERY			TOTALS				
VAR	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	F ratio	df
NPI-OWN	25	17.08	5.27	16	14.63	4.27	41	16.12	4.85	2.44	1/39
NPI-AVG	25	14.68	2.30	16	14.00	1.46	41	14.41	2.00	1.10	1/39
NPI-DOB	25	12.76	4.81	16	12.88	3.35	41	12.80	4.34	0.01	1/39
DDST	21	2.43	0.75	16	2.38	0.72	37	2.41	0.72	0.05	1/35
BSIDMDI	8	99.63	15.97	10	96.10	19.06	18	97.67	17.25	0.17	1/16
BSIDPDI	8	87.38	18.49	10	92.30	23.11	18	90.11	20.58	0.24	1/16
SBIQ	20	92.00	10.72	6	88.17	18.84	26	91.16	12.58	0.41	1/24

APPENDIX K

SURGERY BEFORE ONE YEAR OF AGE
COMPARED TO NO SURGERY BEFORE ONE YEAR--
PHYSICAL AND PSYCHOLOGICAL VARIABLES

Table 22

Surgery Before One Year of Age -vs.- No Surgery Before One Year of Age--
Physical Measurement Variables

For the purposes of this comparison only children who had already undergone surgical intervention were included in the groupings.

GRP	SURGERY BEFORE ONE YEAR			NO SURGERY BEFORE ONE YEAR			TOTALS				
VAR	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	F ratio	df
Weight%	11	26.18	22.94	33	34.64	25.95	44	32.52	24.97	0.92	1/42
Height%	11	43.00	29.53	33	35.27	28.26	44	37.20	28.23	0.60	1/42
Head Circumference%	11	37.27	29.70	33	40.76	28.39	44	39.89	28.37	0.12	1/42

Table 23

Surgery Before One Year of Age -vs.- No Surgery Before One Year of Age--
Psychological Assessment Variables

For the purposes of this comparison only children who had already undergone surgical intervention were included in the groupings.

GRP	SURGERY BEFORE ONE YEAR			NO SURGERY BEFORE ONE YEAR			TOTALS				
VAR	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	N	$\bar{X}$	S.D.	F ratio	df
NPI-OWN	9	17.67	6.20	32	15.69	4.62	41	16.12	4.93	1.11	1/39
NPI-AVG	9	13.44	1.88	32	14.69	2.01	41	14.41	1.96	2.77	1/39
NPI-DOB	9	12.56	4.98	32	12.88	4.23	41	12.80	4.34	0.04	1/39
DDST	9	2.44	0.73	28	2.39	0.74	37	2.41	0.72	0.03	1/35
BSIDMDI	8	99.63	15.97	10	96.10	19.06	18	97.67	17.25	0.17	1/16
BSIDPDI	8	87.38	18.49	10	92.30	23.11	18	90.11	20.58	0.24	1/16
SBIQ	3	91.33	2.08	23	91.09	13.51	26	91.12	12.69	0.00	1/24